

FINDING RELIGIOUS AND SPIRITUAL MEANING IN AIDS-RELATED MULTIPLE  
LOSS: A COMPARATIVE AND CONSTRUCTIVE THEOLOGICAL ANALYSIS OF  
COMMUNAL BEREAVEMENT

A Dissertation

presented to

the Faculty of the

Claremont School of Theology

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

by

Jane Frances Maynard

May 2001

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Jane Frances Maynard

*under the direction of her Faculty Committee, and  
approved by its members, has been presented to and  
accepted by the Faculty of the School of Theology at  
Claremont in partial fulfillment of the requirements for the  
degree of*

**DOCTOR OF PHILOSOPHY**

*Faculty Committee*

Mary Elizabeth Mullins Moore  
Chairperson

Kathleen Gruden

William M. Clement

Date

5/7/01

John R. Pomeroy

## ABSTRACT

### FINDING RELIGIOUS AND SPIRITUAL MEANING IN AIDS-RELATED MULTIPLE LOSS: A COMPARATIVE AND CONSTRUCTIVE THEOLOGICAL ANALYSIS OF COMMUNAL BEREAVEMENT

by

Jane Frances Maynard

The central purpose of this dissertation is to develop a theology and spirituality of bereavement resulting from AIDS-related multiple loss. A second purpose is to describe the implications of this constructive work for emancipatory pastoral praxis. The theological method is a critical correlational practical method. It involves six steps: articulation of pre-understandings; description of the problem of AIDS loss; conversation with a Christian classic; description of a contemporary experience of loss; critical conversation between the classic, the contemporary experience and social scientific research; and, finally, development of a proposal for emancipatory praxis.

In Part I, the method is described, compared with precursors, and related to key theologies on the basis of its aims. The socio-political, psychological, spiritual and theological aspects of the problem of AIDS loss are also considered.

A major thesis is that comparative reflection on the theological response to multiple loss in two historical situations will help to develop a pastorally informed theology and spirituality of bereavement. Part II lays the groundwork for this reflection. It explores a counterpoint to the contemporary experience of AIDS loss, the Black Death pandemic in the fourteenth century, and considers the religious and pastoral response to the plague. The theology and spirituality of the fourteenth century anchoress, Julian of Norwich, are described in light of the plague.



Part III considers the experience of All Saints Church, a San Francisco congregation deeply affected by AIDS loss. A variety of qualitative methods are used to explore the effects of AIDS loss on the congregation's pastoral praxis, theology and spirituality. The grounded theory method guides analysis of the qualitative data.

In Part IV, the historical experience of plague loss, the contemporary experience of AIDS loss, and social scientific literature on traumatic loss are compared in a critical conversation. Themes for the constructive theology arising from this comparison include God, creation, sin, immortality, human nature, and death. Spiritual themes include the importance of self acceptance, self transcendence and a wholistic and honest approach to loss. The implications of the research for contemporary praxis are summarized. The final chapter offers a personal reflection on the research.

## ACKNOWLEDGEMENTS

While writing this dissertation, I have learned that every work of scholarship is a collaborative effort. I would like, therefore, to acknowledge the many collaborators who have aided and cheered me in the course of this work.

First, I am indebted to the people of All Saints Church. I have learned more from them than I ever imagined possible! I am particularly grateful to The Rev. Kenneth Schmidt, rector and my friend, and to The Rev. Lloyd Prator, former rector, for their willingness to share their memories with me. I appreciate the support the Vestry expressed for this research early on. I also thank the parishioners who consented to be interviewed, some more than once. It was a privilege to be with you, and I am grateful for your willingness to re-visit times of sadness and pain as well as joy. I am also thankful for the help of parishioners who generously and promptly completed and returned my survey. Finally, I thank The Rev. Susan J. Singer for sharing her incredible sermon texts, Ralph Wentworth for scouring the Diocesan archives for an important piece of missing data and Lawrence Holbein for willingly sharing the fruits of his research in the parish archives.

I have had many teachers in addition to those noted above. I give thanks for The Rev. Timothy Greene, my supervisor at San Francisco General Hospital many years ago and my fellow traveler in dissertationland. I remember with great affection The Rev. Ted Boya, my mentor at Grace Cathedral who died of AIDS in June of 1992. I fondly remember the support provided by Drs. Arthur G. Holder and L. William Countryman eight years ago when I first began to study the religious and spiritual aspects of AIDS in

earnest. I also remember the many people living and dying with AIDS whom I was privileged to meet in my work as a chaplain.

The members of my committee deserve my gratitude for their support and encouragement. Special thanks go to Dr. Mary Elizabeth Mullino Moore, my chair, and to Drs. Kathleen J. Greider and William Clements. I also appreciate the help of Drs. Karen Jo Torjesen and John Regan at the Claremont Graduate University for their help with historical and methodological materials, respectively.

Others who helped with the writing along the way include Elizabeth Pepin at KQED Television in San Francisco and Elaine Walker at the Claremont School of Theology Library. I appreciate the time The Rt. Rev. William Swing provided when I first began this research. A number of friends helped by reviewing my interview protocol: included here are The Rev. Robert Warren Cromey, The Rev. Canon Frances Tornquist, The Rev. Gerry Shaon and Mrs. Marjorie Campagna-Pinto and Dr. Dante Campagna-Pinto.

I express my deepest appreciation to the Board and Faculty of the Church Divinity School of the Pacific who maintained faith in me during the six year period in which I balanced the demands of teaching, administration and doctoral research. I could not have done this work without your prayers, your patience and your love! Special thanks are due to Dr. Donn F. Morgan, Dean and President, and Dr. Arthur Holder, Academic Dean, for their encouragement and creative problem solving. I am especially thankful for the many gifts and the good humor of The Rev. Ardith Hayes who assisted me ably during the most intense period of this work. I am also grateful to the staff and students of CDSP

who provided encouragement. Special thanks go to Ms. Teresa Vosper who assisted in transcribing and to Mr. John Crowley who helped with the computer.

I appreciate the financial support offered by the Diocese of Idaho Fund for Clergy Education and the Conant Foundation. A grant from the latter made it possible for me to attend the World AIDS Conference in Geneva in the Summer of 1998.

Many friends offered sympathy, encouragement and wisdom along the way. Judy Roska and Maureen Day offered me a home away from home, Janet Kincaid and Judith Bishop provided practical support, Gary and Donna Ramey offered hospitality and prayers, and the Uppity Women's Breakfast Group provided commiseration, advice and fun. Its members are the indomitable Sharon Thornton, Jean Heriot and Ardith Hayes. I also remember fondly the women in my Matristics Class at CGU, especially Debbie Ahlberg and Janet Schaller, who supported my early interest in Julian and the plague. Lynn Euzanas joined with them in supporting my historical interests. I bow to you!

I would like to thank my parents, Paul and Rita Maynard, for providing perspective at important moments. I am grateful to my friend and co-parent, Tom Menten, who sacrificed tremendously to allow me to complete this work. I appreciate his encouragement, financial help and statistical support. He supplied the "long view" when it was needed and never entertained the possibility that I wouldn't finish. My children, Dan and Beckie, also cheered me on. I am grateful to Beckie, in particular, for encouraging me to write a few more chapters for the sake of her report in Health class!

Finally, I am grateful to Jim Treyens for his love and willingness to live with the tortures of writing day in and day out. I appreciate his great generosity in providing many

pleasant diversions. Finally, I am grateful to him for believing in me and for encouraging my dreams for a more just world.

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## INTRODUCTION

My first encounter with AIDS loss came in the Fall of 1987 in Boise, Idaho. I was working as a hospital chaplain; as part of my work, I had the opportunity to attend a day-long workshop on HIV/AIDS for ministers. At this event, I listened to several panelists recount the loss of their loved ones to AIDS. One young woman spoke of her brother's illness and death, while an older woman described in a heartfelt way the premature death of her son. Their poignant stories touched on all the themes one normally encounters in loss: the sadness and pain of grief and sense that our loved ones who have died are irreplaceable. There was, however, another element to these stories that shocked and upset me, namely the stigmatization that these families had experienced as, time and time again, participation in the simplest rituals of illness and death were denied them. These included, for example, the tremendous difficulty the young woman experienced in finding a mortician who would receive her brother's body following his death. This difficulty also constituted an AIDS-related loss. I could only begin to fathom the pain, anger and sense of dehumanization that might accompany such treatment. I was horrified by their stories and filled with rage at their mistreatment. At the same time, I understood the real fear of contagion that motivated these indignities.

This event provided my introduction to the social and emotional complexities of HIV disease and AIDS loss. This experience awakened in me twin desires for *justice and mercy*. I wanted, in a cosmic sense, to right the wrongs that people with AIDS were experiencing and to learn to minister to them with love, while honestly acknowledging in myself and others the fear and outright horror that the encounter with AIDS can represent.



My horror then and now springs as much from the devastating nature of the disease as from its potential for unmasking the worst within us: our fear of difference, our desire to ensure our own safety by creating antiseptic zones of likeness, and our tendency simply to shut down in the face of others' pain, which renders us helpless.

One aim of this work is to develop a theology and spirituality of AIDS loss drawing on my pastoral experience and research. The theology and spirituality developed in this work may be understood, according to Rebecca Chopp, as a response to a moral summons implicit in the panelists' testimony twelve years ago.<sup>1</sup> In the same way that I felt a call then to respond to the injustice and indignity of human pain through pastoral work, the articulation of a theology and spirituality of AIDS loss in this work represents my attempt to express the implications of this profound loss for the Christian imaginal world. As Chopp rightly notes, theology shaped in response to the moral summons of testimony discerns

transcendence as the power and spirit of transfiguration. . . . God, as the term of transcendence, functions as hope, the promise of liberation.<sup>2</sup>

My aim is to create a theology and spirituality that inspire hope in the face of suffering arising from AIDS and AIDS loss.

My conviction is that far too many people have died from HIV disease and that many of those deaths could have been prevented. The global consequence of AIDS loss is suffering. Like Chopp, I affirm the power of the Spirit to transfigure the experiences and memories of suffering, so that they may empower the creation of a new and more just

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<sup>1</sup> Rebecca S. Chopp, "Theology and the Poetics of Testimony," *Criterion* 37 (winter 1998): 2.

<sup>2</sup> *Ibid.*, 10.

world for all of us who live with HIV disease.<sup>3</sup> Like Chopp, I also affirm the presence of God in the acts of remembering our beloved dead, in shaping a new life among survivors, in critiquing the present, and in creatively naming future possibilities for a more just world.<sup>4</sup>

Chopp notes that transcendence is a moral summons to imagine hope. Therefore, my second intention in this work is to describe a concrete hope, a hope embodied in the theology and practice of Christian communities that have confronted unthinkable death with unshakable courage and have met a self-giving love that transcends death. The fruit of hope in these communities is resurrection life, a life of justice empowered by the dangerous memories of love to which they testify. I offer the present work as one empowered and enriched by the memories of loved ones. I pray that it will contribute to the continuing transfiguration of their loss for the benefit of the whole world.

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<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

## **Part I**

### **Method and Problem**

## CHAPTER 1

### MAKING A WORLD TOGETHER

This seems to me to be the challenge to theology, to do theology in a way that recognizes it as a kind of performative knowledge, which is what Christian understanding is meant to be. . . . I would alter theology's definition from *fides quarens intellectum* (faith seeking understanding) to *fides quarens mundum agendum propter Deum* (faith seeking the kind of world that should be acted out, because of who God is).<sup>1</sup>

The central purpose of this work is to understand the enormous suffering that may be attributed to AIDS loss and to explore how a dialogue between the Christian tradition and the contemporary experience of AIDS loss may result in just and wise practices to relieve pain. To achieve this aim, three things are required: first, careful description and analysis of the pain associated with AIDS loss; second, exploration of resources from the culture and tradition that may be brought to bear upon AIDS loss; and third, concrete proposals for its amelioration. This is indeed a demanding enterprise.

This chapter will provide a road map for this analytical, theological and practical exploration. The exploration of AIDS loss will begin and end in the realm of pastoral practice. First, we shall consider how the guiding concerns of this work arose from my reflection on pastoral experience as an AIDS chaplain nearly ten years ago. Using the language of hermeneutic theory, I shall then attempt to describe how this work and my reflection upon it shaped my "pre-understandings" of the pastoral issues associated with

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<sup>1</sup> Bernard J. Lee, "Practical Theology as Phronetic: A Working Paper from/for those in Ministry Education," *APT Occasional Papers* 1 (winter 1998): 11.

AIDS loss.<sup>2</sup> After considering these concrete influences, the theological aims and method of this work will be explored. Borrowing from Lee, we shall envision “a world we want to make together.”<sup>3</sup> The aims of this work will then be described and situated in relationship to some key types of theology, including liberation theology, practical theology, pastoral theology and revisionist theology. This discussion will clarify the purpose of the project and name influences that have guided its conception. Following this discussion, the method developed to address the identified aims will be described. Along the way, this method will be compared to other contemporary theological methods and their contributions to this project explored. The imaginative dimension of the project will involve description, historical comparison and theological reconstruction. The exploration will then come full circle; the final step is to articulate the implications of the constructive theological work for “emancipatory praxis.”<sup>4</sup> The chapter will conclude with an overview of the dissertation as a whole.

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<sup>2</sup> My use of the term “pre-understandings” is influenced by Don S. Browning in his work, *A Fundamental Practical Theology: Description and Strategic Proposals* (Minneapolis: Fortress Press, 1991), 38. Browning adopts this terminology from Hans Georg Gadamer’s *Truth and Method* (New York: Continuum, 1975), 235, 261.

<sup>3</sup> Lee, “Practical Theology as Phronetic,” 2.

<sup>4</sup> I am indebted to Rebecca S. Chopp and Mark Lewis Taylor for this term. According to these authors, “emancipatory praxis embodies the reconstructions forged by theologians in community and the reconstructions they offer to an array of other communities they face in a pluralistic global life. . . . Central to theology is the issuing of new proposals for communal life, a form of “corporate grace” that promotes corporate (original emphasis) empowerment and flourishing.” Since the proposals for praxis in this dissertation arose from a community’s experience and reflect a communal vision, the term “emancipatory praxis” seems most appropriate. See their essay, “Introduction: Crisis, Hope and Contemporary Theology,” in *Reconstructing Christian Theology*, ed. Rebecca S. Chopp and Mark Lewis Taylor (Minneapolis: Fortress Press, 1994), 21-22.

### **A Pastoral Encounter with AIDS Loss**

In this section, the pre-understandings I bring to the hermeneutic analysis of HIV/AIDS and their rootedness in my pastoral experience will be described. This description will be a phenomenal description of my first encounter with the central problem addressed in this dissertation: the multiple losses associated with HIV disease and AIDS. An analytical description of the problem will follow in Chapters 2, 3 and 4. Both types of description -- the praxis-based description I have provided in this chapter and the more comprehensive socio-political, psychological, theological, and spiritual description in the second, third and fourth chapters -- are important to the present method. However, I have chosen to present this more "subjective" description of the problem as a way of introducing the present method. This is because the pre-understandings I bring to this work were significantly shaped through my pastoral experience, and because articulation of them influences the more "objective" description and analysis of the problem.

As I noted in the introduction, my life with HIV/AIDS began in 1987 when I attended a workshop entitled "AIDS: Perspectives in Pastoral Care" at St. Luke's Regional Medical Center in Boise, Idaho. In those days, AIDS was rare in Idaho. In my five years of experience as a hospital chaplain (from 1984-1989), I did not encounter a single person living with AIDS. However, my preliminary experience at the workshop kindled within me a desire for mercy and justice for those living with AIDS and their loved ones.

My experience with AIDS changed dramatically in 1990-91 when I began to work as a seminary intern in the Episcopal Chaplaincy Program at San Francisco General

Hospital. At SFGH, I worked on Ward 5A, the Inpatient AIDS unit, where I met many persons who were living with AIDS. My work at SFGH challenged me intensely. I became most vividly aware of the destructiveness of AIDS, the stigmatization that persons with AIDS and HIV encounter, and the hope and healing that can come through loving acceptance of and care for persons with AIDS. I was particularly moved by the dedication of the nursing staff on 5A, who provided comfort and love day after day to many individuals.

My work with persons living with AIDS forcefully confronted me with the reality of death. Many patients I visited were close to my age or younger, and I mourned the tremendous loss of potential that AIDS brought about in their lives.

AIDS began to assume a personality for me -- I visualized it as a chameleon that took differing and unpredictable forms in each individual. At times, AIDS also appeared to me as an adversary without face or form and battling it had life-changing effects. It seemed to oppose all that was creative and life-giving. How could I make sense of the disease? Where could I and the individuals living with HIV/AIDS find hope in the presence of AIDS? My work with persons with AIDS provided the greatest theological challenge I have ever experienced. During this period, my theological questions had two main foci: understanding the nature of God and God's response to suffering and reconciling my perception of the goodness of creation with what I perceived as the destructiveness of AIDS.

At the same time as I wrestled explicitly with these questions, I was also troubled by another concern during my year of work as an AIDS chaplain. This concern centered on the nature of my identity as a pastoral caregiver. As I have already indicated, I

experienced in AIDS ministry the greatest theological challenge I have ever faced. My foundational understandings of God, creation, and human nature and destiny were totally shaken. I was overwhelmed by this cognitive onslaught at the same time as I was overwhelmed by the enormity of AIDS loss in San Francisco in the early nineties. Perhaps the most significant challenge I faced, however, arose from the caregiving model that characterized my work as chaplain.

To describe this challenge, I shall rely on the excellent analysis of caregiving models provided by Larry Kent Graham.<sup>5</sup> Adopting Graham's terminology, I would characterize the dominant model of caregiving within the chaplaincy program at SFGH as an "existentialist-anthropological" model. According to Graham, such models have as their goal the health and fulfillment of individuals. The emphasis in them is individualistic; caregivers subscribing to them give priority to encouraging careseekers to identify and express what they think and feel. In Graham's view, such models largely neglect social ethics, as they place the personhood of the careseeker in the foreground and the context in the background. In his review of current approaches to pastoral care and counseling, Graham does note examples of theorists who work more explicitly with contextual issues, including Don Browning, John Patton, Charles Gerkin, Archie Smith,

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<sup>5</sup> See the excellent discussion of the existential-anthropological model of care in Larry Kent Graham, *Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counseling* (Nashville: Abingdon Press, 1992), 32-38.



Jr. and Howard Clinebell.<sup>6</sup> In fact, Graham's characterization of Clinebell's empowerment approach, with its emphasis on the integration of personal and social healing, seems most akin to chaplaincy as I experienced it at that time. Like Graham, however, I found this approach to chaplaincy ultimately unsatisfying because it did not attend adequately to the systemic forces that create and perpetuate injustice. Neither Clinebell's theory nor the others Graham reviews go far enough in their attempts to explore the relationship between individual and social transformation, particularly as they are affected by pastoral care.

Given the nature of the staff and clients at SFGH, a city and county hospital of last resort, it would be unfair to say that contextual issues and issues of oppression were ignored. On the contrary, there was a great deal of sensitivity to issues of oppression and power cultivated within the Episcopal chaplaincy, and chaplains were trained well to attend to issues of heterosexism and homophobia, in particular. However, while there was some emphasis on empowerment, I would agree with Graham that, as in Clinebell's work, the definition of wholeness encouraged within the chaplaincy tended to "assume that whole persons would automatically contribute to whole societies, without recognizing that the definitions of wholeness participate in an individualism that [is] at the root of many of our difficulties."<sup>7</sup>

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<sup>6</sup> See, for example, Browning, *Fundamental Practical Theology*; John Patton, *Pastoral Care in Context* (Louisville: Westminster John Knox Press, 1993); Charles Gerkin, *Widening the Horizons: Pastoral Responses to a Fragmented Society* (Philadelphia: Westminster Press, 1986); Archie Smith, Jr., *The Relational Self: Ethics and Therapy from a Black Church Perspective* (Nashville: Abingdon Press, 1982); and Howard Clinebell, *Basic Types of Pastoral Care and Counseling: Resources for the Ministry of Healing and Growth*, rev. ed. (Nashville: Abingdon Press, 1984).

<sup>7</sup>Graham, *Care of Persons, Care of Worlds*, 38.

In considering the effects of this model, I think it is important to acknowledge its implications for both the careseeker and caregiver. The difficulty it creates for both, and one that I experienced firsthand, is that the model tends to focus almost exclusively upon the private realm and tends to minimize the effects that social and political dysfunction have upon individual well-being. In addition, the model encourages both the caregiver and the careseeker to rely upon their autonomous resources, rather than encouraging them to draw upon resources from the wider web of relationships in which each is embedded. Thus, both parties in the therapeutic relationship experience an oversight of potential resources that may be brought to bear on the problem. In my case, this proved quite crippling. I found that I was overwhelmed by the magnitude and extent of AIDS loss, as the burdens of care we were experiencing as chaplains in those days sapped my theological, emotional and spiritual resources considerably.<sup>8</sup>

When facing these challenges, I found myself wrestling with the nature of the chaplaincy and my relationship to the wider Christian community that I represented as caregiver.<sup>9</sup> It seemed to me imperative in the face of enormous challenges associated

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<sup>8</sup> Besides the failure of the chaplaincy's model of caregiving, my distress also arose from the failure of my suburban congregation to address adequately the suffering of AIDS. Thus, I felt isolated in my chaplaincy work and it seemed to have little relationship to the larger ministerial concerns of the congregation in which I worshipped.

<sup>9</sup> I should note here that my relationship to the Christian community was often more implicit than explicit in the caregiving relationship at SFGH. The chaplaincy program was sponsored by the Episcopal Diocese and was funded through the Diocesan budget and through parishioner giving to Episcopal Charities Appeal. Further, the chaplaincy directors were Episcopalians. However, most of the volunteer chaplains were not Episcopalian, and some were not Christian. Many were described as "unaffiliated spiritual journeyers" and were drawn to the program by its fine reputation and the excellence of its mission, exemplified in its commitment to providing high quality care and loving support to persons living with AIDS. While my identity as an Episcopalian influenced the character of the care I provided, I often did not share my particular religious affiliation with those to whom I ministered, who were themselves of varying to no religious affiliation.

with AIDS that I learn as a pastoral caregiver to draw on the resources of the entire Christian community in my pastoral work and to discover how the Church could benefit from my experience. At that time, therefore, I found myself asking questions such as the following: What forms of care are needed in the face of the varying challenges -- psychological, theological, spiritual and socio-political -- that AIDS represents? How are individual and communal forms of care interrelated? What relationship exists between care providers and the communities they represent? What difference might these relationships make within the pastoral relationship? Finally, what theological and spiritual resources are present within the Christian tradition to address adequately the theological challenges AIDS represents and how may the community as a whole mobilizes these resources to promote healing? Addressing these questions provided an incentive for the present work. In fact, my commitment to exploring systemic models of care and their implications for AIDS represents an important prejudice that has influenced this project.

It is possible for me to identify a number of other prejudices that I bring to the task of interpretation. These include the desires I initially brought to my practice of AIDS ministry, desires for justice and mercy, and my conviction that stigmatization undermines human dignity. Other pre-understandings relate to aspects of my identity. They include my upbringing as a Roman Catholic and my present role as an Episcopal priest. These strands of my identity reflect a commitment to liturgical prayer and regular spiritual practice and an appreciation of the rich tradition of Christian spirituality. They are also expressed in a sacramental understanding of life, a Trinitarian (communal) understanding of the nature of God, a threefold notion of authority and a commitment to social justice

that is exemplified in both the Anglo-Catholic and evangelical traditions of Anglicanism. Also central to my identity are commitments to a feminist understanding of pastoral care and counseling and an understanding that Jesus Christ offered a powerful witness to God's all-embracing love. The latter understanding, in particular, conflicts with my experience of racism, sexism and heterosexism in the Episcopal Church.<sup>10</sup>

Other prejudices arise from my status as a divorced heterosexual white woman who is highly educated, with a considerable background in psychology and theology. My training in the social sciences has definitely influenced the methods I have used to explore AIDS loss in this work. Also central to this project's execution are significant experiences of personal loss, including the loss of my close friend to AIDS. These losses have given me first-hand experience with the bereavement process, and I have drawn on them in interpreting others' experiences of loss. Finally, other pre-understandings, including the dissatisfaction with the limitations of the existentialist-anthropological model, grew out of my prior praxis. Included here are two commitments to affirmations that I articulated in my prior AIDS ministry: belief that the power of love is greater than the power of suffering and death, and belief that the work of creation is ongoing, involving human risk and benefiting from our efforts as co-creators with the Divine.<sup>11</sup>

An important aspect of the present work is examining the interaction of these pre-understandings with my reading of tradition and contemporary praxis. For now, it is

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<sup>10</sup> Perhaps the clearest exemplar of feminist pastoral care and counseling is Christie Cozad Neuger. While she has written extensively on this subject, I have been most influenced by her article, "Feminist Pastoral Theology and Pastoral Counseling: A Work in Progress," *Journal of Pastoral Theology* 2 (summer 1992): 35-57.

<sup>11</sup> I expressed and developed these beliefs in an unpublished manuscript entitled, "Suffering is Not the Final Word: A Theology of Pastoral Care to Persons with AIDS," San Francisco, April 1991.

simply important to note that my prior practice of AIDS ministry has contributed passions and commitments to the present investigation, both of which have considerably shaped the design of this work.

### **Theological Aims in Relationship to Current Trends in Theology**

The overall aim of this project is to contribute to the development of an emancipatory praxis of pastoral care that is adequate to the experience of AIDS-related multiple loss.<sup>12</sup> The development of this proposal for transformed praxis will be based on a careful description of the experience of AIDS loss and an imaginative reconstruction of Christian theology and spirituality related to the pastoral care of persons living with it. Two questions will be primary: What kind of world do we want to make in the face of these realities and what actions will be required to achieve the transformation we desire?<sup>13</sup>

Articulation of the more specific aims guiding this project may add nuance and clarify the relationship of this work to contemporary theologies. Therefore, I shall

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<sup>12</sup> The term *praxis* is variously defined. The definition I most favor comes from Bernard Lee who speaks of *phronesis/praxis* in a single breath. In his view, *phronesis* is knowledge about the kind of world people should be working together to create, while *praxis* is appropriate human action flowing from such knowledge. Another way of expressing this is to think of *phronesis* as "know how" and *praxis* as "how to." Wedding the two as Lee does underscores the inextricable relationship between action and reflection. In addition, Chopp and Taylor's emphasis on the communal nature of praxis is consistent with the aims of this project which understands AIDS loss, first, as communal in nature since AIDS has had particular impact on specific communities and, second, as exacerbated by systemic forms of oppression, most notably racism, sexism and heterosexism. See Bernard J. Lee, "Practical Theology as Phronetic," 1; and Chopp and Taylor, "Introduction," 15. Finally, I am indebted to David Tracy for the criteria of adequacy, which is particularly crucial in the face of the devastation AIDS represents. See David Tracy, *Blessed Rage for Order: The New Pluralism in Theology* (New York: Seabury Press, 1975), 29.

<sup>13</sup> I am indebted to Lee for the form of the question. See Lee, "Practical Theology as Phronetic," 14. Both Tracy and Browning highlight the centrality of attending to theories of transformation as they relate to praxis. See David Tracy, "The Foundations of Practical Theology," in *Practical Theology*, ed. Don S. Browning (San Francisco: Harper & Row, 1983), 76; and Browning, *Fundamental Practical Theology*, 278-93.

describe the aims of this study with respect to four contemporary movements: liberation theology, practical theology, pastoral theology and revisionist theology.

Turning first to liberation theology, the present work shares with liberation theology and political theology a common starting point: the human experience of suffering, particularly as it is exacerbated by oppression.<sup>14</sup> My hope is, first, that this work will take seriously the suffering associated with AIDS loss and give voice to those who suffer. This contribution is particularly crucial since one effect of the stigmatization associated with AIDS is to silence those living with AIDS and those who experience AIDS losses.<sup>15</sup> Second, my intention in this project is to affirm the full humanity and dignity of all persons living with HIV disease and AIDS loss. This affirmation is based on my awareness that those most heavily affected by HIV disease and, thus, AIDS loss are the marginalized: the poor, gays and lesbians, women, IV drug users, the hemophiliac community, children and youth, and people of color throughout the world. Structures of oppression that create their marginalization have contributed to widespread denial and minimization of HIV's effects upon them, and this, in turn, has affected their access to medical treatments and aids to prevention. My affirmation of the human dignity of those living with HIV is based on my conviction that all people are of great worth because they

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<sup>14</sup> See Chopp and Taylor, *Reconstructing Christian Theology*; and Rebecca Chopp, *The Praxis of Suffering: An Interpretation of Liberation and Political Theologies* (Maryknoll, N.Y.: Orbis Books, 1986), 2.

<sup>15</sup> My interviews with HIV-positive individuals support the effect of stigmatization in silencing these individuals. The literature on multiple AIDS-related loss witnesses to the effect of stigmatization on silencing bereaved loved ones. See, for example, David Nord, *Multiple AIDS-Related Loss: A Handbook for Understanding and Surviving a Perpetual Fall* (Washington, D.C.: Taylor & Francis, 1997), 62.

are created in God's image.<sup>16</sup> Finally, my understanding of anthropology is also consistent with that of liberation theology which examines human nature in relationship to the social systems that shape personhood.<sup>17</sup>

Consistent with this understanding, another aim of this work is to identify and analyze systemic issues that intensify the suffering associated with AIDS. These include first, the failure of the political systems in the United States, the global community and the Church to respond consistently and in a loving and timely fashion to the crisis of AIDS.<sup>18</sup> Second, I hope to address at least briefly the effects of differential access to treatment around the world, as this issue affects the demographics of AIDS loss. Further, I will speak out against the growing complacency about AIDS in my own community, the Episcopal Church in the San Francisco Bay Area. Access to improved treatments in the San Francisco Bay Area has diminished concern for those suffering from AIDS. The exploration of these issues of oppression and systemic failure in the face of AIDS expresses my central concern for justice, a motivating force for the work at hand.

A final parallel between the aims of this work and those of liberation theology grows from the emphasis on communal praxis in liberation theology. It is important to

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<sup>16</sup> See Larry Kent Graham, *Discovering Images of God: Narratives of Care among Lesbians and Gays* (Louisville: Westminster John Knox Press, 1997) for a sophisticated discussion of the concept *imago dei*.

<sup>17</sup> See Rebecca S. Chopp and Duane F. Parker, *Liberation Theology and Pastoral Theology*, JPCP Monograph, no. 2 (Decatur, Ga.: Journal of Pastoral Care Publications, 1990), 13.

<sup>18</sup> For the failure of political systems, see John-Manuel Andriote, *Victory Deferred: How AIDS Changed Gay Life in America* (Chicago: University of Chicago Press, 1999); for the failure of global systems, see World Bank, *Confronting AIDS: Public Priorities in a Global Epidemic* [book online] (New York: Oxford University Press, 1997, accessed 30 Apr. 2000); available from <http://www.worldbank.org/aids=econ/confront/confrontfull.html>; for the failure of the church, see World Council of Churches, *Facing AIDS: The Challenge, The Churches' Response: A WCC Study Document* (Geneva: WCC Publications, 1997), 5.

note that the vision for transformed praxis emerging from this work is strongly rooted in the experience of a particular community, namely All Saints Episcopal Church in San Francisco. My interaction with the members of this community has deepened my understanding of life with AIDS and AIDS loss, and the members of this community have served as my reflection partners in this project. Their input was indispensable in developing the constructive theology I articulate in this work. I hope with the aid of their reflection to deconstruct theological symbols and doctrines that enforce notions of the sinfulness of homosexuality, sex, and AIDS and to reconstruct the notion of sin to include the oppression and exclusion of gays, lesbians and people of color from full participation in the Episcopal Church.

A second theological tradition that shares certain aims with the present work is practical theology. According to Seward Hiltner, the term “practical theology” was probably coined by Marheineke, but was made famous by Schleiermacher in the nineteenth century.<sup>19</sup> The aim of practical theology, as defined by Schleiermacher, was to study the theology that arose from the Church’s “operations and actions.”<sup>20</sup> Thus, the development of practical theology arose from the recognition that reflection on the practice of ministry yielded theological insights that were not “apart from or contradictory to the findings of biblical, doctrinal and other theological studies, but [were] complementary to them.”<sup>21</sup> A key aim of practical theology, therefore, was to explore

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<sup>19</sup> Seward Hiltner, “Introduction to Practical Theology as a Theological Discipline,” photocopy, Princeton Theological Seminary, Student-Faculty Seminar in Practical Theology, 21 October 1963, 1.

<sup>20</sup> Ibid.

<sup>21</sup> Ibid.



theological insights arising from the varied expressions of the Church's ministry. A further aim was to flesh out the theological contributions that various sub-disciplines of practical theology, such as homiletics, liturgics, and pastoral care could make to theology and the practice of ministry, conceived more broadly.

As Osmer's historical overview of practical theology makes clear, the understanding of the nature of practical theology has evolved considerably through several distinct phases since the time of the Reformation, when it was most closely associated with the emergence of ethics as a distinct form of theological reflection within Protestantism.<sup>22</sup> Even today, considerable variation remains in understanding the aims of practical theology. In her review of the diverse aims of practical theology in the United States, Mary Elizabeth Mullino Moore identifies seven primary aims. These include:

1. guiding the life of the church
2. uniting the arts of ministry or practical disciplines
3. promoting the development of theology in relation to social context
4. contributing to social analysis and critical public discourse
5. contributing to ethical behavior
6. contributing practical wisdom to theology, and
7. contributing to social transformation.<sup>23</sup>

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<sup>22</sup> Richard Osmer, "Teaching as Practical Theology," in *Theological Approaches to Christian Education*, ed. Jack L. Seymour and Donald E. Miller (Nashville: Abingdon Press, 1990), 216-38.

<sup>23</sup> Mary Elizabeth Mullino Moore, "The Aims of Practical Theology: Diversity in the United States," published as "La Theologie Pratique aux Etats-Unis: Une Diversite d'Options," *Cahiers de l'Institut Romand de Pastorale* 24 (Mars 1996): 3-17.

Of these diverse aims, the ones closest to the heart of the present work include guiding the life of the church, contributing to social analysis and public discourse and contributing to social transformation. My attempt to shape an emancipatory praxis for the care of those living with AIDS and AIDS loss will be directed first toward guiding the church's practice of pastoral care. Second, the fact that I have built upon the revisionist method of mutual critical correlation in the present work reflects my desire to dialogue with analyses of AIDS and AIDS loss in the public realm. Theologians have significant expertise to offer to the public dialogue about AIDS. Theological contributions have been perceived as marginal to the public debate, however, because the perspectives that have been offered to it most frequently reflect orthodox rather than revisionist approaches.<sup>24</sup> Finally, although I am influenced by the revisionist approach, my primary concern is with "the critique and transformation of oppressive situations where life is being destroyed" rather than with building knowledge, *per se*; hence, my interest in social transformation.<sup>25</sup>

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<sup>24</sup> This trend was particularly apparent to me when I had the opportunity to attend the 12<sup>th</sup> World AIDS Conference in Geneva, June 28-July 3, 1998. Of the roughly two hundred paper sessions and workshops held at this conference, only one session focused directly upon religion and HIV. This section featured three speakers, one of whom focused on the debate on condom use within the Roman Catholic Church. The limited nature of this symposium and the scant attention devoted to theological and spiritual issues in this setting cries out for a revisionist approach, one that would empower theologians to participate as full and equal partners in the public arena. For the distinction between orthodox and revisionist approaches to theology, see Tracy, *Blessed Rage for Order*, 22-42. For an understanding of the theologian's work as a resource in public debate, see David Tracy, *The Analogical Imagination: Christian Theology and the Culture of Pluralism* (New York: Crossroad, 1981), especially chaps. 1 and 2. Of course, the marginalization of theology in Western society may limit the degree of influence that even well-developed revisionist perspectives can have.

<sup>25</sup> Moore, "Aims of Practical Theology," 16. This important theoretical distinction was voiced most clearly by Rebecca Chopp. See her chapter entitled "Practical Theology and Liberation," in *Formation and Reflection: The Promise of Practical Theology*, ed. Lewis S. Mudge and James N. Poling (Philadelphia: Fortress Press, 1987), 131.

In addition to aims shared with liberation theology and practical theology, this study of AIDS loss shares some features with the tradition of pastoral theology. Pastoral theology itself may be understood as a sub-discipline of practical theology. Like liberation theology, pastoral theology also begins with the experience of suffering. The distinctive emphasis in pastoral theology is on the care of persons and “it finds personality theories, particularly within psychology, primary resources for the enhancement of this practice.”<sup>26</sup> Traditionally, as Miller-McLemore notes, the object of study in pastoral theology is “*the study of living human documents rather than books.*”<sup>27</sup> She also states that in the past decade, feminist pastoral theologians, in particular, have modified the individualistic emphases of the field. They have greatly increased the attention paid to social context. As practitioners focus on breaking silences, urging prophetic action and liberating the oppressed, pastoral care is increasingly adopting liberationist perspectives. As Miller-McLemore observes, “pastoral theology is critical reflection on [these activities].”<sup>28</sup> This dissertation is clearly aligned with this growing liberationist emphasis within the field of pastoral theology. Other emphases in this work consistent with the field of pastoral theology include the incorporation of theories and methods from the human sciences. My use of the writings of Julian of Norwich to shed light on contemporary experience is an example of the recovery of pastoral resources from the classical Christian tradition. Introducing such resources is another aim that I

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<sup>26</sup> Bonnie J. Miller-McLemore, “Feminist Theory in Pastoral Theology,” *APT Occasional Papers* 2 (fall 1998): 7.

<sup>27</sup> Ibid. (original emphasis).

<sup>28</sup> Ibid.

share with some contemporary pastoral theologians.<sup>29</sup>

The final theological strand of importance to this work has already been introduced, namely, revisionist theology. This term arises in the work of David Tracy, who uses it to describe a type of theology

committed to what seems clearly to be the central task of contemporary Christian theology: the dramatic confrontation, the mutual illuminations and corrections, the possible basic reconciliation between the principal values, cognitive claims and existential faiths of both a re-interpreted post-modern consciousness and a reinterpreted Christianity.<sup>30</sup>

Tracy describes the method of mutual critical correlation as ideally suited to this dialogue between authentic secularity and the Christian faith. We shall note momentarily that I have drawn heavily from this method in the present investigation. I have chosen to do so, in part, because I hope to offer a revisionist theology that will enable those suffering from AIDS loss to find, within the human experience of loss, resources for an ultimate faith and hope. An important grounding for these qualities may be found in the dangerous memories of suffering and resurrection expressed in the paschal mystery. Like Tracy, I believe that theology can profit from a healthy dialogue with the social sciences. We may benefit particularly from those psychological studies that have greatly enriched our understanding of the quest for meaning the encounter with AIDS and AIDS loss

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<sup>29</sup> Both Thomas Oden and Donald Capps draw upon the tradition in their theoretical work. See Thomas C. Oden *Care of Souls in the Classic Tradition* (Philadelphia: Fortress Press, 1984); and Donald Capps *Biblical Approaches to Pastoral Counseling* (Philadelphia: Westminster Press, 1981).

<sup>30</sup> Tracy, *Blessed Rage for Order*, 32.

triggers.<sup>31</sup> Any attempt to find theological and spiritual meaning in the face of AIDS must consider carefully the sheer magnitude of human suffering and loss that people living with AIDS have endured. The quest for meaning has particular urgency in the epicenters of infection like San Francisco, where entire generations within certain communities have been virtually annihilated by the disease. Tracy's criterion of adequacy offers a particularly useful reflection tool in such extreme situations.<sup>32</sup>

Now that exploration of the theological aims of the present work is complete, let us turn to a description of the method. I shall first describe the method and then explore it in relationship to important methodological precursors.

### **Description of the Method**

The development of an emancipatory praxis for the care of persons experiencing multiple AIDS-related loss will involve six steps. The method begins with *articulating the pre-understandings* that the theologian brings to the task of interpretation. I have already outlined certain pre-understandings that have arisen from my life experience and prior pastoral ministry. As I noted, the articulation of pre-understandings is an important aspect of the work of interpretation, as it helps the theologian to be aware of his or her biases and how they may affect the interpretation of texts and practices and the development of theory. Further, careful examination of these pre-understandings may

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<sup>31</sup> One especially useful resource in this discussion is the excellent work of Steven Schwartzberg who addresses the urgent search for meaning and hope HIV-positive gay men experience in his book, *A Crisis of Meaning: How Gay Men are Making Sense of AIDS* (New York: Oxford University Press, 1996).

<sup>32</sup> Tracy, *Blessed Rage for Order*, 44. The criterion of adequacy requires theologians to demonstrate the adequacy of the major Christian theological categories for all human experience.

allow for a more integrated understanding as they may be consciously assimilated into the newly created theory.<sup>33</sup>

The second step of the method includes *identifying and describing the problem at hand* -- the effects of multiple AIDS-related loss -- in its various aspects. We shall explore five in particular: socio-political, religious, psychological, theological and spiritual understandings of AIDS loss. Further, in describing the experience of AIDS loss, we shall engage in ideology critique: that is, we shall attempt to discern ways in which Christian theological symbols and doctrines may be implicated in the creation of problems posed by AIDS and AIDS loss.

The next part of the analysis, following the description of the problem, will be the development of a descriptive practical theology. Here, we shall engage in two sorts of hermeneutical dialogue. In step three of the method the description of AIDS loss will be placed in *conversation with a Christian classic*, the writings of Julian of Norwich, a fourteenth century mystic. Julian will serve as a critical dialogue partner for the investigation of AIDS loss. I have chosen to work with Julian's theology because it was developed in a time of multiple loss. It arose during the several waves of the Black Death that swept through England from the mid-fourteenth century. I shall first describe the context in which Julian's theology developed and then explore her theology in relationship to it. Investigating Julian's theology will serve four purposes. First, it will highlight common features of the human experience of multiple loss. Second, it will

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<sup>33</sup> This understanding of the effect of the interpreter's pre-judgments is from Gadamer and is cited in Browning, *Fundamental Practical Theology*, 38. Browning also provides helpful examples of the ways in which prior studies of congregations have been unwittingly influenced by unacknowledged pre-understandings researchers have brought to the task of interpretation (pp. 110-35).

place unique aspects of multiple AIDS-related loss in relief. That is, it will help us to discern which features of AIDS loss are unique and which may be found in other situations of multiple loss. Third, it will clarify important cultural aspects of multiple loss. Fourth, it will also suggest important psychological and theological themes to inform analysis of multiple AIDS-related loss. As an anchoress and a woman, Julian occupied a marginal position in her own society; her perspective, offered from the margins in her day, may empower theologians in our time to benefit from her courage when reflecting on their experiences of AIDS loss.

In step four of the method we shall engage in a contemporary hermeneutical dialogue, *focusing on a contemporary experience* of loss and the theological and ministerial response to it. This portion of the study begins with an ethnographic description of the experience of multiple AIDS-related loss sustained by the congregation and members of All Saints' Episcopal Church in the Haight-Ashbury district of San Francisco. This congregation, a pastoral church, conducted thirty-four AIDS funerals from the early eighties to the mid-nineties, and losses due to AIDS affected virtually every aspect of the church's life.<sup>34</sup> A variety of qualitative methods will be used to assess the manifold effects of this loss on the life of the congregation as a whole.

There are three important reasons for studying a congregation's experience of AIDS loss. First, it will allow theologians and caregivers to explore the nature of communal loss, as distinguished from individual loss. This approach offers particular promise, since the effects of AIDS loss have been felt most strongly in certain

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<sup>34</sup> Arlin Routhage uses the term "pastoral church" to describe churches with fifty to one hundred and fifty active members. See *Sizing Up a Congregation for New Member Ministry* (New York: Episcopal Church Center, [1989?]).

communities: among gay men, hemophiliacs, IV drug users and people of color. Second, focusing on the praxis of a congregation will encourage movement beyond a strictly clerical paradigm in developing an emancipatory praxis of pastoral care in AIDS loss. Third, exploring the life of a congregation will uncover the contributions of a variety of theological and ministerial resources, including liturgy, Christian education programs, preaching, social service and pastoral care as it has traditionally been defined. The goal of this description will be to identify the central theological, pastoral and ethical questions raised for the congregation in its experience of AIDS loss and to explore the theological and spiritual understandings and praxis they have formed in response.

The fifth step of the method is *a critical conversation*. We shall construct a dialogue between the questions and answers emerging from the human experiences of individual and communal AIDS loss and the questions and answers arising from the classical and contemporary religious sources. This analysis will involve several steps. First, the theological understandings of Julian will be compared with those of the All Saints' community to determine similarities and differences. In the words of David Tracy, we shall ask, "What mode of being-in-the-world does each suggest?"<sup>35</sup> The adequacy of each theological world view for the present situation will then be assessed in light of the analysis of the problem of AIDS loss. Third, in light of this analysis and the ideological critique, we shall consider whether and how to reconstruct classical theological formulations in light of the experience of multiple AIDS loss. Finally, these theological and spiritual formulations will also be assessed in light of psychological

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<sup>35</sup> Tracy, *Blessed Rage for Order*, 52.



approaches to traumatic loss. This analysis will help to nuance further the constructive theological work. The end result of this analysis will be the articulation of a theology and spirituality of multiple AIDS-related loss that draws from historical formulations, contemporary praxis and the human sciences to address the full complexity of this phenomenon.

In the final step of the method, we shall return to the questions with which we began: What kind of world do we want to make in the face of these realities and what actions will be required to achieve the transformation we desire? This analysis will culminate in a *proposal for an emancipatory pastoral praxis* designed to address the challenges of multiple AIDS-related loss. We shall also consider the limitations of the present research, and the implications of this work for pastoral approaches to bereavement and to multiple loss in the congregational setting.

### **A Comparative Analysis of Critical Correlation**

To conclude this discussion of method, a comparison with several important predecessors can highlight the unique features, strengths and aims of the critical correlation method.

The first theologian to propose a method of correlation was Paul Tillich. He described his method in the following way:

In using the method of correlation, systematic theology proceeds in the following way: it makes an analysis of the human situation out of which the existential questions arise, and it demonstrates that the symbols used in the Christian message are the answers to these questions.<sup>36</sup>

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<sup>36</sup> Paul Tillich, *Systematic Theology*, vol. 1 (Chicago: University of Chicago Press, 1951), 62.

However, as David Tracy accurately points out in *Blessed Rage for Order*, Tillich's method may be rightly characterized as a juxtaposition rather than a correlation, because if the human "situation" is to be taken seriously, then it must also investigate its answers to its own questions. As Tracy notes in his wry way, "...No one (not even a Christian theologian!) can decide that only *the questions* articulated by a particular form of contemporary thought are of real theological interest."<sup>37</sup> Therefore, Tracy offers the following definition of a truly correlational method.

There are two sources for theology (common human experience and language, and Christian texts); those two sources are to be investigated by a hermeneutic phenomenology of the religious dimension in common human experience and language and by historical and hermeneutical investigations of the meanings referred to by Christian texts; the results of these investigations should be correlated to determine their significant similarities and differences and their truth values.<sup>38</sup>

The major advances Tracy offers, therefore, are the description of theology as a thoroughly hermeneutical enterprise and his insistence that dialogue between the two sources -- human experience and the Christian tradition -- be mutually critical. As Browning puts it, Christian theologians "must, in principle, have this critical conversation 'with all other answers,' from wherever they come."<sup>39</sup>

Browning, building on the work of Tracy, offers another helpful observation. He notes that adoption of a hermeneutical understanding of theology suggests that theology must be seen as fundamentally *practical*, with a primary focus on theory-laden practice,

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<sup>37</sup> Tracy, *Blessed Rage for Order*, 46.

<sup>38</sup> Ibid., 53.

<sup>39</sup> Browning, *Fundamental Practical Theology*, 46.

rather than fundamental with a primary focus on cognitive and transcendental verification.<sup>40</sup> He notes:

Fundamental theology, according to Tracy, determines the conditions for the possibility of the theological enterprise. If the conditions for theology are significantly influenced by the close association between hermeneutics and *phronesis* as I outlined above, then fundamental theology would determine the conditions for the possibility of a theology that would be seen first as dealing with the normative and critical grounds of our religious practice. This is what I mean by a fundamental practical theology [original emphasis].<sup>41</sup>

This emphasis is thoroughly consistent with the understanding guiding this investigation.

Perhaps the most scathing critique of the critical correlational method is offered by Rebecca Chopp.<sup>42</sup> She argues that the critical correlational method is linked to a liberal theology that construes religion and theology in a way that may not be adequate to the present situation. The chief limitation of the method, in her view, is that it masks the compliance of Christianity with bourgeois existence. Her preference is for the aims and method of liberation theology. In addressing her critique, let us consider her principle arguments, one by one.

Chopp's first critique of the revisionist project is that it attempts to address the crisis of cognitive claims of the bourgeois non-believer as opposed to the practical challenge of the poor who are victimized by economic and political systems promoting injustice.

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<sup>40</sup> Ibid.

<sup>41</sup> Ibid, 47. Browning notes that in this statement he is building upon the work of Matthew Lamb and Rebecca Chopp. See Matthew L. Lamb, *Solidarity with Victims* (New York: Crossroad Publishing, 1982); and Chopp, "Practical Theology and Liberation."

<sup>42</sup> See Chopp, "Practical Theology and Liberation."

Her second critique relates directly to the correlational method: Chopp argues that its treatment of the sources of experience and tradition is flawed. In her view, the method privileges the experience of white bourgeois males, treating it as “common human experience.” Second, the classics in the tradition from which it draws are those authorized by the ecclesial and theological elite. Further, she argues that the nature of the correlation between experience and tradition is always theoretical; thus, the method promotes the dominance of theory over practice.

Chopp’s third critique focuses on the limits of praxis in the revisionist approach. First, she claims that in the revisionist approach, praxis is understood as intentional activity rather than a broad web of relations in which an individual’s doing and being are contained. Second, she argues that, in contrast to liberation theology, the intent of reflection in the revisionist method is a desire to reconcile subjects to the universe through understanding, rather than to promote critique and transformation of the social order. Finally, she believes that the understanding of politics in the revisionist approach is too limited, for politics is understood as a limited area of concern rather than an integral part of all theological reflection. She faults revisionist theology for failing to adopt the option for the poor that is the chief aim of liberation theology.<sup>43</sup>

I believe that Chopp’s critiques of the revisionist project as *the project has been executed to this point* are sound. However, dismissing the method because of its cognitive nature and its privileging of understanding over praxis seems unduly harsh. Theology must strive both for understanding *and* transformation. Without an adequate

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<sup>43</sup> These arguments are described in Chopp, “Practical Theology and Liberation,” 132-36.

understanding of the tradition and present praxis, it will be difficult to move effectively toward a transformed praxis. I will show that it is possible to work toward a more politically aware and “suspicious” use of the method of critical correlation. The method can be used effectively to reflect on the experience of suffering and, further, can recapture aspects of the tradition that have been overlooked or mistreated by past interpreters. The fact that it has not been critically applied in the past does not automatically rule out its usefulness in the future for addressing the need for emancipatory praxis. The introduction of critique and the judicious use of sources, along with correlation, will allow the method of critical correlation to serve as an important tool in understanding injustice and its effects and also in promoting transformed praxis.

In light of this methodological review, several features of this project’s method merit notice. First, the focus is clearly on justice and the political and systemic factors that promote it. This emphasis flows in large part from the nature of the problem itself. Second, the phenomenon of suffering associated with AIDS is primarily a form of suffering that has been experienced by the marginalized; thus, we shall be examining a particular experience of suffering. We shall do well to remain mindful of the limits imposed by this particularity. Third, the historical analysis will draw on the experience of a marginalized interpreter of the tradition, Julian of Norwich, rather than on a theologian perceived as elite. Julian was chosen because of her promise for enhancing a comparative study of multiple loss. Fourth, in developing a proposal for emancipatory praxis, we shall focus on the praxis of a particular community; the community, an Episcopal parish in San Francisco, may also be understood as marginal within its denomination because of its relatively large percentage of gay and lesbian members. Therefore, while the focus

will be partly on understanding, the approach will equip readers to address oppression and move toward a more just pastoral praxis. My hope is that the particular path we have chosen will avoid some of the serious flaws that can limit the critical correlational method, flaws that Chopp has helpfully articulated.

### **Overview of the Dissertation**

Now that we have explored the foundation for the emancipatory praxis method, let us anticipate its application. In the remainder of Part One, we shall identify and describe the problem posed by multiple AIDS-related loss. We shall explore five key perspectives: the socio-political, religious, psychological, theological and spiritual dimensions. The aim of this exploration is to provide a thick description of the human experience of AIDS loss. This analysis will lay the foundation for the later historical, descriptive and correlational work.

Part Two is an exploration of the fourteenth century context of Julian of Norwich, considering the ways in which her theology and spirituality were shaped through the experience of plague loss. This analysis will help clarify further the human experience of multiple loss and provide an important point of comparison for the contemporary experience of AIDS loss.

In Part Three, we shall consider the life and ministry of All Saints Episcopal Church in San Francisco. All Saints is a congregation that was deeply affected by AIDS loss. We shall use a variety of methods to examine the effects of this loss and explore the implications of it for the theology and spirituality of that community and its members.

In Part Four, the theologies and spiritualities that arose in fourteenth century Norwich and twentieth century San Francisco in response to the experience of multiple

loss will be compared. We shall also review important social-scientific research on traumatic loss to see how it may contribute to a theology and spirituality of AIDS loss. Finally, key themes will be identified for a constructive theology and spirituality of multiple AIDS loss, drawing from the historical, descriptive and social scientific work and from the critical conversation between them.

In Chapter 11, we return to the original questions: What kind of world do we want to make together and what praxis will be required to achieve it? Here we shall consider important qualities for a transformed world and some concrete steps to respond to the pain of AIDS loss.

Finally, Chapter 12, a more personal reflection, will provide an account of the effects of the research on my emotional experience, theology and spirituality.

My sincere hope is that this exploration will illuminate the reader's search for a transformed world. May it point the way toward more just, compassionate and realistic care of those who continue to suffer from the perplexing and painful experience of AIDS loss.

## CHAPTER 2

### TOWARD AN ETHIC OF SOCIAL SOLIDARITY: IDENTIFYING AND CONFRONTING THE SOCIAL, POLITICAL AND RELIGIOUS ASPECTS OF AIDS LOSS

The history of AIDS has shown that HIV can enter a community or country in many different ways. In each country, where and among whom HIV enters obviously defines the early history of the epidemic. ...However, with time, as the epidemic matures, it evolves and moves along a clear and consistent pathway, which, although different in its details within each society, nevertheless has a single, vital and common feature. For in each society, those people who were marginalized, stigmatized and discriminated against -- before HIV/AIDS arrived -- have become over time those at highest risk of HIV infection. Regardless of where and among whom it may start within a community or country, the brunt of the epidemic gradually and inexorably turns toward those who bear this societal burden.<sup>1</sup>

In the end, the policy challenge is to articulate *an ethic of social solidarity* in the face of an epidemic that does not affect all equally. This issue must also be joined on a global level. How will the wealthy industrial nations with relatively small or stable HIV epidemics respond to the nations of the world that are poor and medically impoverished and that face the burden of an ever-increasing prevalence of HIV infection? It is in the answer to these questions that the future of the global epidemic of HIV/AIDS will lie.<sup>2</sup>

The purpose of this chapter is to identify and describe four key dimensions of AIDS-related multiple loss. First, the magnitude of AIDS and AIDS loss around the world and in San Francisco will be documented. Then, three aspects of the problem of

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<sup>1</sup> Jonathan M. Mann and Daniel Tarantola, "From Vulnerability to Human Rights," in *AIDS in the World II: Global Dimensions, Social Roots, and Responses*, ed. Mann and Tarantola, Global AIDS Policy Commission (New York: Oxford University Press, 1996), 463-64.

<sup>2</sup> Ronald Bayer, "Societal and Political Impact of HIV/AIDS," in *AIDS in the World II*, ed. Mann and Tarantola, 122 (emphasis mine).



AIDS loss crucial to the current analysis will be investigated. These include the social dimensions of AIDS loss, political factors affecting the spread of AIDS and magnitude of AIDS loss, and the response of religious communities to AIDS. Each of these factors has an important bearing on the development of a theology and spirituality of AIDS loss and the shaping of an emancipatory praxis.

### **Establishing the Extent of the Problem: Documenting The Magnitude of AIDS Loss**

Since the late 1970s, AIDS, the Acquired Immune Deficiency Syndrome, has claimed the lives of 16.3 million men, women and children throughout the world.<sup>3</sup> The greatest number of deaths by far is in Africa south of the Sahara where an estimated 13.7 million people have died from AIDS. South and Southeast Asia rank second in AIDS deaths with 1.1 million. Latin America ranks third with an estimated 520,000 deaths and North America is fourth with an estimated 450,000 deaths.<sup>4</sup>

In addition to those who have already died, an estimated 33.6 million men, women and children currently live with HIV/AIDS. In the year 1999 alone, 5.6 million people worldwide became infected with the human immunodeficiency virus. Further, 1999 also witnessed 2.6 million deaths from HIV/AIDS, a higher global total than in any year since the beginning of the epidemic. The death toll continues to mount despite the existence of antiretroviral therapy. The latest UNAIDS report projects that the global

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<sup>3</sup> UNAIDS and WHO, *AIDS Epidemic Update: December, 1999*, UNAIDS/99.53-WHO/CDS/EDC/99.9 – WHO/FCH/HIS/99.6, [text on-line] (Geneva: UNAIDS Information Center, English original, December, 1999, accessed December 15, 2000); available from <http://www.unaids.org>, 2.

<sup>4</sup> Ibid., 23.

death toll from AIDS will continue to mount for many years before peaking because of the continued rise in the numbers of people infected with HIV.<sup>5</sup>

Examination of the data on HIV incidence and death demonstrates that ninety-five percent of the people around the world who live with HIV may be found in developing countries. There is a clear relationship between poverty and the risk of HIV infection, and infection rates are growing fastest in countries with poor health systems and limited resources for prevention and care.<sup>6</sup> Populations at particular risk include the young, especially young women. According to the UNAIDS 1999 surveillance report, half of all people who acquire HIV become infected before they become 25. They also tend to die from opportunistic infections associated with AIDS before they become 35. Many of these people are in their prime childbearing years and leave children behind. By the end of 1999, the cumulative total of AIDS orphans, defined as those having lost their mother before the age of 15, was 11.2 million worldwide.<sup>7</sup>

Despite the fact that people living with HIV/AIDS in industrialized countries typically have greater access to antiretroviral therapy, the presence of these drugs has not eliminated concern about prevention or infection rates. According to the UNAIDS report, there is some evidence that “the advent of life-prolonging therapies may have led to complacency about the dangers of HIV and . . . the complacency may be leading to

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<sup>5</sup> Despite the advances that antiretroviral medicine have made possible, these drugs are not widely available to those in the poorest nations. See Chap. 11 below. Further, even where they are available, they may decrease vigilance and thus, they do not provide an absolute safeguard against rising infection rates. See the evidence from San Francisco cited on the next page.

<sup>6</sup> UNAIDS and WHO, *AIDS Epidemic Update*, 4.

<sup>7</sup> Ibid.

risks in risky behavior.”<sup>8</sup> Evidence to support this conclusion is drawn from a study of male sexual behavior in San Francisco. This study demonstrated that the proportion of men reporting anal sex without a condom rose from just over one-third in 1993-4 to one-half in 1996-7 following the increased availability of more effective treatments.

Additional evidence suggests that there may be limits to the effectiveness of these therapies; the dramatic fall in AIDS deaths seen in the first three years following the introduction of these therapies is beginning to taper. In the United States, for example, AIDS deaths decreased by 42% between 1996 and 1997, but by only half that proportion between 1997 and 1998.<sup>9</sup> Comparable trends have been observed in Europe. Clearly, people in both developing and industrialized nations continue to be threatened with the possibility of infection and death from HIV disease in this, the fourth decade of the AIDS epidemic.

The particular focus of the present study is on AIDS-related loss in San Francisco. From July of 1981 to December of 1999, the city of San Francisco experienced the deaths of 18,164 people to AIDS.<sup>10</sup> The cumulative number of AIDS cases in San Francisco as of December 1999 was 26,616. At the present time, there are roughly 8,500 people living with AIDS in San Francisco. Further, the total deaths from AIDS in San Francisco

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<sup>8</sup> Ibid., 10.

<sup>9</sup> Ibid., 10.

<sup>10</sup> The population for the city of San Francisco was estimated at 724,000 according to the 1990 U.S. Census. See Campbell Gibson, “Population of the 100 Largest Cities and Other Urban Places in the United States: 1790 to 1990,” [text on-line] (Washington, D.C.: U.S. Bureau of the Census, Population Division, June 1998, accessed 6 March 2001); available from <http://www.census.gov/population/www.documentation/twps0027.html#tabA>. Incidence Data is from the San Francisco Department of Public Health. See also San Francisco Department of Public Health, “AIDS Surveillance Quarterly Report, December 1999,” [text on-line] (San Francisco: Department of Public Health, 1999, accessed 6 March 2001); available from <http://www.dph.sf.ca.us/PHP/RptsHIVAIDS/qtrrpt1299.pdf>.

with AIDS in San Francisco. Further, the total deaths from AIDS in San Francisco represent almost one quarter of the deaths from AIDS in California and nearly four percent of AIDS deaths in the United States. Clearly, San Francisco deserves its characterization as an epicenter of the AIDS pandemic in the United States, and one would be hard put to find a resident of the city who has not been touched by AIDS loss in some way.

The data on the prevalence of AIDS, taken as a whole, document both the enormous losses that can be attributed to AIDS, and the certainty that millions of people around the world will continue to be touched economically, psychologically and spiritually by AIDS loss. The global magnitude of AIDS loss provides an important rationale for the present investigation.

### **The Social Dimensions of AIDS Loss**

As the data on the magnitude of AIDS loss suggest, not all people are equally at risk of experiencing AIDS and AIDS loss. The UNAIDS surveillance report clearly demonstrates that the epidemic has taken different forms in different parts of the world. In some areas, like Africa south of the Sahara, HIV is primarily transmitted through heterosexual activity, and women, particularly young women, are at greater risk of contracting HIV disease than men. This is due, in part, to women's greater vulnerability

arising from a complex interrelationship of biological, social and economic factors.<sup>11</sup> In the former Soviet Union, one of the fastest growing areas of infection in the world, the bulk of new HIV infections is caused by the unsafe injection of drugs. In San Francisco, in contrast, the greatest percentage of infection and loss has occurred among gay and bisexual men.

The unequal distribution of HIV/AIDS within and across geographical areas has introduced the need to attend to both the social and political factors associated with AIDS and AIDS loss.

#### Social and Economic Factors Associated with Transmission of HIV

In addition to the geographical factors we have already noted in infection trends, certain social factors influence the frequency with which individuals engage in risky sexual behavior. Consequently, these factors have a bearing on the size of the epidemic. According to the 1997 World Bank Report, *Confronting AIDS: Public Priorities in a Global Epidemic*, there are eight epidemiological, social and economic variables that can explain about two thirds of the variation in cross-country HIV infection rates.<sup>12</sup> The first variable is income: when other variables are held constant, both low income and

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<sup>11</sup> A number of factors contribute to women's increased risk. First, women have greater biological vulnerability than men. Research shows that the risk of becoming infected with HIV during unprotected vaginal intercourse is as much as 2-4 times higher for women than men. Further, women are more vulnerable than men to other sexually transmitted diseases which also increase the risk of HIV infection. Besides their greater illiteracy, other social factors increase women's risk. Being married can be a major risk factor for women who have little control over abstinence or condom use at home and their husbands' extramarital sexual activity. Finally, AIDS prevention campaigns often fail women by assuming that they are at low risk or advocate prevention methods, such as condom use, that women often have little power to apply. See UNAIDS, *Women and AIDS: UNAIDS Point of View*. UNAIDS Best Practice Collection Point of View (Geneva: UNAIDS, October 1997).

<sup>12</sup> World Bank, *Confronting AIDS: Public Priorities in a Global Epidemic*, [book on-line] (New York: Oxford University Press, 1997, accessed April 30, 1999); available from <http://www.worldbank.org/aids=econ/confront/confrontfull/chapter 1. Sub 3.html>, 1.

unequally distributed income are strongly associated with HIV infection rates. According to the World Bank report, a \$2000 increase in per capita income in the average developing country is associated with a reduction of about 4 percentage points in the HIV infection rate of urban adults. Clearly, rapid and fairly distributed economic growth, in and of itself, will help to slow the AIDS epidemic.<sup>13</sup>

The second set of variables associated with higher HIV infection rates pertains to gender inequality. First, it is important to note that the combination of gender inequality and poverty are hypothesized to place both men and women at greater risk of infection. Women who are poor, either absolutely or relatively to men, may find it harder to take steps in their sexual relationships to protect themselves from the risk of contracting HIV. Poorer men may also be more prone to having sex with multiple partners than men with more resources. This difference may result because poverty may inhibit a man's ability to attract a wife or cause him to leave home to search for work.<sup>14</sup>

In assessing the impact of variables related to gender inequality independently of other variables, authors of the World Bank report controlled for the percentage of the population that is Muslim.<sup>15</sup> They also controlled the per capita gross national product, the presence of income inequality and certain other social characteristics. The results

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<sup>13</sup> Ibid. The authors also note that improving per capita income and reducing gender inequality may stimulate the spread of HIV, since factors associated with economic growth also increase the risk of infection. See page 2 of Chap. 1, subsection 3.

<sup>14</sup> Ibid.

<sup>15</sup> The authors controlled for the percentage of the population that is Muslim because this provided a way of assessing the effects of gender independently of Muslim belief. They hypothesized that Muslim belief is likely to be correlated with gender inequality across countries.

indicate that two variables related to gender inequality appear significant. First, a higher ratio of males to females in urban centers correlates with a higher rate of HIV infection. The authors hypothesize that this correlation arises from the likelihood that men in areas with fewer women will avail themselves of commercial sex workers. This factor, in turn, is associated with an increase in HIV. The authors note further that, in an average developing country, when job opportunities in urban areas rise for young women, with a corresponding decrease in the ratio of males to females, then one can expect a decrease in the HIV infection rate.<sup>16</sup>

The second variable related to gender inequality is literacy. The authors examined the relationship between male and female literacy rates and susceptibility to HIV infection. The literacy rate was as much as 25 percentage points higher among men in some countries. Further, a higher gap between male and female literacy rates is correlated with an increased risk of HIV infection for women. The authors assume that unequal literacy rates reflect women's greater economic dependence on men. They infer that this factor results in women's decreased ability to bargain for the use of condoms and for sexual equality. This assumption appears to be borne out by the data that suggest that countries that reduce the literacy gap between genders by 20 percentage points can expect a 4 percent decrease in the urban HIV infection rate.<sup>17</sup>

One conclusion does seem clear: naiveté about gender inequality among AIDS educators places women at increased risk. As June Osborn notes: "it became clear in

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<sup>16</sup> Ibid.

<sup>17</sup> Ibid. When the ratio falls from 1.3 to 0.9, the HIV infection rate drops by about 4 percentage points.

early AIDS prevention efforts. . . that exhorting a woman to insist on condom use might well place her in harm's way with a sex partner who held abusive power."<sup>18</sup> Thus, women's unequal power may place them at greater risk of infection, since they have less control over their sexual fate.

The third cluster of factors that increases the prevalence of HIV infection is associated with the dynamics of economic growth. The size of immigrant populations is a key economic factor. The data indicate that countries with larger immigrant populations tend to have larger AIDS epidemics. Typically, these countries are open to trade, financial flow and the movement of people across their borders. Countries in which 5 percent of the population is foreign born can expect to have an infection rate that is 2 percentage points higher, on the average, than countries without a foreign born population.<sup>19</sup> In addition, certain development programs designed to stimulate the economy of a region may carry increased risk for HIV. Sometimes, as in the case of the Chad-Cameroon pipeline, governments can take steps to decrease the risk of infection to workers. In considering the risks accompanying such projects, the authors conclude:

Economic development projects that do not generate sufficient net economic returns after covering the cost of mitigating negative impacts,

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<sup>18</sup> June Osborn, "Are We Learning from the Lessons of the Past?," in *AIDS in the World II*, ed. Mann and Tarantola, 306.

<sup>19</sup> World Bank, *Confronting AIDS*, 2. The authors of the report take care to indicate that this finding does not justify either restricting immigration or screening out HIV-positive immigrants. The former action is likely to decrease growth, thereby contributing to risk; the latter is unlikely to be effective since immigrants have a greater risk of contracting HIV after they have left their homes and established social networks. Further, attempts to screen immigrants can drive those infected "underground" and make it more difficult to educate them about prevention.



including the spread of AIDS, should be rejected as undesirable -- even if the gross returns are quite large.<sup>20</sup>

The next social factor associated with the increased risk of HIV and AIDS in rapidly growing countries results from the broad shift from conservative social norms to more liberal attitudes. According to the World Bank report, countries with a high degree of social conservatism have significantly lower HIV rates.<sup>21</sup> In general, the movement toward greater liberality and toward increased equality for women appears to be correlated with both rapid growth and an increased risk of HIV infection.

The final risk factor associated with an increased rate of HIV infection includes the level of militarization of a country. Countries with more soldiers have a greater risk of infection. When an average country reduces the size of the military from 30 to 12 percent of the urban population, it can expect to experience a 4 percent decrease in the rate of HIV infection.<sup>22</sup>

These data from the World Bank provide a means for identifying larger social and economic factors associated with an increased risk of HIV infection. With decreased infection comes decreased loss of lives. The data, therefore, supply an important source

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<sup>20</sup> Ibid., 3.

<sup>21</sup> In the absence of objective measures of social conservatism, the regression analysis used the percentage of Muslim population in the countries studied as "an imperfect proxy for a country's degree of social conservatism." Ibid.

<sup>22</sup> Ibid. The authors of the report do not consider the reasons for this correlation between militarization and the increased risk of HIV infection, aside from the fact that military forces are often based near urban centers and are likely to consist of large numbers of young, unmarried men. Two factors that may influence this correlation are first, the fact that military cultures tend to promote the use of sex workers. See Rita Nakashima Brock and Susan Brooks Thistlewaite, *Casting Stones: Prostitution and Liberation in Asia and the United States* (Minneapolis: Fortress Press, 1996), 75-78 for the relationship between sex and violence in military culture. Second, the disruption from support systems that occurs while men are in military service may increase the stress experienced by soldiers and, thus, the likelihood of riskier sexual behaviors.

of information that may be used in political, educational, and social efforts to minimize the ever-growing impact of AIDS and AIDS loss.

### Social Groups at Risk: Vulnerability Analysis

Besides this data on larger social trends, existing data also suggest the need to attend to social factors within particular groups that may have a bearing on the rate of infection. Epidemiological research has pinpointed groups that may be at increased risk of infection, including the young, women, IV drug users, gay men and blood recipients. Research has also determined that the susceptibility of members of these groups to infection varies from place to place. For example, gay men are at greater risk of infection in San Francisco, while intravenous drug users are at greater risk in the former Soviet Union. Also, as Mann and Tarantola note, social conditions affecting the perception of these groups' members may hamper prevention efforts. They note that

recent work [with existing population groups] has identified a social dimension that is the critical missing element in prevention programs. In various ways, depending upon the group being considered, society seems to be interfering with more effective HIV prevention. Thus, for youth, social ambivalence about autonomy and responsibility is highlighted; among homosexual men, social stigma still constitutes a formidable barrier to effective prevention; among heterosexuals, the social role and status of women seems vital to future progress; and for blood recipients in the developing world and prisoners in most countries, a lack of social will impedes progress. . . . Future success in HIV/AIDS prevention will hinge upon the development of a capacity to understand and to respond to the missing social dimensions.<sup>23</sup>

Understanding how social perceptions interact with other risk factors to affect the rate of HIV infection is crucial to slowing the rate of infection throughout the world.

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<sup>23</sup> Mann and Tarantola, "Response: Individuals and Populations," in *AIDS in the World II*, ed. Mann and Tarantola, 213.

In an attempt to address contextual issues, Mann and Tarantola propose that public health practitioners and others working with AIDS prevention and treatment consider the need for vulnerability analysis. Vulnerability analysis begins with the recognition that not all individuals have either equal ability or equal means to control their own health. For example, we have already noted certain factors, such as decreased literacy, that place women at greater risk of infection. Vulnerability analysis assumes that a variety of factors may influence the varying susceptibility to infection that characterizes such groups. In employing vulnerability analysis, one must attend to factors such as governmental structures, gender relationships, attitudes towards sexuality, religious beliefs, and poverty, as each of these may affect personal vulnerability to HIV. The goal of vulnerability analysis is “to expand people’s capacity to exert control over their own health.”<sup>24</sup>

According to Mann and Tarantola, variables in three categories of contextual factors affect vulnerability to HIV. These categories of contextual factors include political and governmental factors, socio-cultural factors and economic factors. Political and governmental factors include such phenomena as governmental interference with the free flow of information pertinent to HIV/AIDS; a lack of HIV/AIDS services; and official or sanctioned discrimination against HIV-infected people and people with AIDS. This discrimination may be in the areas of employment, insurance, health care, marriage, travel or residence. Socio-cultural factors are associated with gender roles, attitudes towards sexuality, and the stigmatization and marginalization of certain groups. Finally,

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<sup>24</sup> Mann and Tarantola, “Social Vulnerability: Contextual Analysis,” in *AIDS in the World II*, ed. Mann and Tarantola, 461.

economic factors include poverty and income disparity, lack of resources for prevention programs and lack of employment opportunities. Contextual analysis that attends to the fullest range of influences affecting vulnerability provides the greatest hope for effective intervention and prevention.

An important advantage of vulnerability analysis is that it helps to highlight the need for deep and sustained social change in addressing the problems that lead to the proliferation of AIDS. In keeping with this emphasis, Mann and Tarantola also advocate the adoption of a human rights approach to identifying and addressing:

the root causes, or the underlying conditions of society which create and sustain vulnerability to HIV. . . . The insight that vulnerability to HIV/AIDS depends upon the extent to which human rights are realized and human dignity is respected within each society (and among societies) creates an opportunity to intervene at the deepest societal level, and thereby combat the pandemic.<sup>25</sup>

Thus, there is an inextricable relationship between vulnerability and human rights. This relationship grows out of the recognition that many forces beyond the immediate control of individuals, including political, economic, cultural, and social forces influence the behavior of individuals, affecting, as Mann and Tarantola indicate, the capacity for health-promoting behavioral change.<sup>26</sup> Despite this fact, public health approaches to HIV prevention have often failed to consider the influence of larger, societal forces on health. Two factors, in particular, have heightened public health workers' awareness of the need for vulnerability analysis in managing rising HIV infection rates. First, the people at highest risk of HIV infection in *any* society are those who were marginalized, stigmatized

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<sup>25</sup> Mann and Tarantola, "From Vulnerability to Human Rights," in *AIDS in the World II*, ed. Mann and Tarantola, 463.

<sup>26</sup> *Ibid.*, 464

and discriminated against before HIV arrived.<sup>27</sup> Second, analysis of the limits and failures of existing prevention programs indicates that, without a consideration of human rights, these programs will continue to fail.<sup>28</sup> For example, women's risk of contracting HIV infection often has more to do with their male partner's sexual behavior than their own. In Kigali, Rwanda, twenty percent of HIV infected women had only a single lifetime sexual partner, while in Morocco, forty-five percent of infected women have been infected by their husbands.<sup>29</sup> As long as prevention efforts fail to acknowledge and address women's inferior roles and subordinate status, their vulnerability to HIV infection will continue to grow, particularly in areas of great poverty where multiple sexual partnerships may be a major route of access for women to resources.<sup>30</sup>

A human rights analysis of vulnerability requires three steps:

- First, it is important to identify the societal and contextual factors that influence vulnerability to HIV within a specific community or society.
- Second, one must then identify violations of the specific human rights underlying each of the contextual factors.
- Finally, one must determine the concrete actions that are needed to improve respect for the human rights identified as important to that context.<sup>31</sup>

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<sup>27</sup> Ibid. (emphasis mine).

<sup>28</sup> Ibid., 465.

<sup>29</sup> Ibid.

<sup>30</sup> Ibid.,

<sup>31</sup> Ibid., 469-71.

The goal of human rights analysis is empowerment. According to Mann and Tarantola, empowerment results when people realize that some important aspect of their lives can be different and that change is possible.<sup>32</sup> Not only are individuals empowered when their human rights are respected, but their health also improves. Public health workers and other professionals stand to gain an increased sense of efficacy as they confront the social roots of ill health, affirm the dignity of those they serve and cooperate with all sectors of society to promote health.

### **Political Aspects of AIDS**

The following observation from the World Bank report describes the normative political response to HIV/AIDS.

Country after country responded to evidence of the first infections by saying, 'We are different. AIDS cannot strike us.' Each has been proven wrong. When countries discovered that they indeed did have a fatal, sexually transmitted disease spreading rapidly in their midst, one after another responded by cleaning up the blood supply or conducting general awareness campaigns, while avoiding or devoting insufficient resources to efforts to encourage safer behavior among people most likely to contract and spread the virus.<sup>33</sup>

As this analysis suggests, HIV/AIDS confronts political leaders with difficult and unpopular decisions. The World Bank report points out four types of issues that have repeatedly posed problems for policy makers in assessing the political impact of AIDS. They include denial, reluctance to help people most at risk of infection to avoid the

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<sup>32</sup> Ibid., 475.

<sup>33</sup> World Bank, *Confronting AIDS*, chap. 6, part 4, 1.

infection, a preference for moralistic responses, and pressure to spend money on treatment at the expense of prevention.<sup>34</sup>

Denial is most prominent in the early stages of the epidemic when the long asymptomatic period masks the presence of HIV. In some societies, politicians fail to acknowledge that extramarital sex and drug use exist in the society, in part, because these activities may be clandestine in the most conservative societies. However, even when politicians are aware of these behaviors, they may be unwilling to initiate the kind of frank discussions that could lead to an effective HIV prevention program.

Second, politicians often feel little pressure to focus prevention programs on those most likely to contract the disease, including commercial sex workers, intravenous drug users, gay and bisexual men and their partners, and others with multiple sexual partners. Frequently, their reluctance is due to the fact that they and their constituents fail to understand the links between infection in the general population and those in high risk groups. Further, those in high risk groups sometimes block prevention efforts focused upon them because of fear of increasing discrimination and backlash. In the face of such pressures, politicians opt for general public information campaigns, even when these are less likely to prevent the spread of HIV.

Third, a preference for moralistic responses often leads politicians to opt for less effective interventions. For example, they may advocate abstinence from sex and drug

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<sup>34</sup> Ibid., chap. 1, part 5, 1-2.

use instead of providing free condoms or clean needles to those at greatest risk of infection.

Finally, as epidemics become more generalized, politicians may divert funds from prevention to pay for treatment and care.<sup>35</sup> Unfortunately, such actions may lead to increased sickness and death in the long run.

Describing these four obstacles helps to capture some of the political difficulties that can accompany the rise of political awareness around HIV/AIDS. The response to the epidemic in the United States, however, was marked by other pitfalls as well. These included, first, hubris, a false confidence in biomedical science which led to a hampered appreciation of the role that behavioral science or any other discipline could play in prevention; second, the changing nature of urban society which placed many homeless people at increased risk of infection; third, the development of visual communication strategies for prevention materials that featured (presumably) gay white men and led women and people of color to a false sense of confidence; and, finally, resistance in

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<sup>35</sup> This possibility follows from the fact that as the epidemic grows in a given area, it increases the demand for medical care and reduces its supply at a given quality and price. As the number of HIV infected people rises, access to medical care becomes more difficult and expensive for everyone, including people not infected with HIV, and total health expenditures rise. In this situation, governments will likely experience pressure to increase their share of health care spending and to provide special subsidies for the treatment of HIV. Because a large share of the increased health care expenditure typically comes through tax revenues, countries will face tradeoffs between treating AIDS vs. preventing HIV infection, treating AIDS vs. treating other illnesses and spending for health care vs. spending for other objectives. Based upon a mathematical assessment of the costs of AIDS in developing countries, the World Bank suggests that paying a larger share of health costs and subsidizing treatment costs is likely to be imprudent for many countries. The report concludes, therefore, that "a prudent course would be to consider any expansion of government-financed health care subsidies or insurance only in conjunction with vigorous prevention programs that enable people most likely to contract and spread HIV to protect themselves and others." World Bank, *Confronting AIDS*, chap. 4, subsection 2, 8. See the extended discussion of health care costs associated with AIDS in developing countries and suggestions for humane responses governments can make to the AIDS epidemic in chap. 4 of the World Bank Report.



school districts against sex education, despite epidemic rates of teenage sexual activity.<sup>36</sup>

Political decisions related to each of these factors, in addition to the four mentioned above, helped to fuel the rising rate of HIV infection within the United States.

Unfortunately, poor political decisions also led to an increased death toll, particularly in the early years of the AIDS epidemic.

In conclusion, therefore, attending to aspects of both the social and political climate plays a crucial role in formulating an effective response to HIV disease. To the extent that societies and policy makers rise to the challenges posed by HIV/AIDS, significant strides can be made in prevention.<sup>37</sup> To the extent that these factors are minimized or ignored, the epidemic is allowed to spread unchecked and the result is massive death, economic struggle and boundless suffering from the ravages of AIDS and AIDS loss.

### **Religious Aspects of AIDS Loss: How the Churches Contributed to the Spread of AIDS**

The response of the American Christian Churches to the spread of AIDS was disappointingly slow and theologically flawed. Despite the fact that the first published reports of AIDS appeared in the press in the summer of 1981, most churches did not address the issue of AIDS publicly until the mid-eighties. James Ayers, in his study of the response of the American evangelical churches to AIDS, notes that “the three most

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<sup>36</sup> Osborn, “Are We Learning from the Lessons of the Past?”, *AIDS in the World II*, ed. Mann and Tarantola, 302-06.

<sup>37</sup> The World Bank Report documents particularly effective strategies that have been adopted in Thailand and Mexico. Appropriate governmental response has helped to turn the rising tide of infection in each of these countries.

predominant Christian attitudes towards the AIDS pandemic . . . [were] apathy, judgment and fear.”<sup>38</sup>

### The Churches’ Response to AIDS

Several factors influenced the churches’ pattern of response. First, as J. Gordon Melton notes in his review of the contemporary debate in the churches on the AIDS crisis, the churches invariably drew upon two long-standing philosophies in responding to the AIDS crisis. The first was the view that sexuality outside of marriage is sinful; the second was the ethic of love and service. Emphasizing the first view might lead churches to censure those who contracted the HIV virus through extramarital sexual activity. Emphasizing the second view would lead to an imperative of ministry to the sick, regardless of the cause of their illness. In responding to this dilemma, religious groups had to integrate facts about the epidemic, their moral and theological perspectives on sexuality and sexually transmitted diseases, and their imperatives about ministry to the sick and dying. In evaluating the position of a particular church, Ayers states that

The positions arrived at depended on whether more importance was assigned to the moral condemnation of AIDS victims for engaging in disapproved sexual activity or to the more pressing demands of compassion in a time of severe need.<sup>39</sup>

The first response by churches in the United States to the emergence of AIDS came in May of 1983, when the National Council of Churches issued a statement calling for increased funding for AIDS research and increased public education. Following this statement, a group of churches weighed in early and positively in responding to the AIDS

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<sup>38</sup> James R. Ayers, “The Quagmire of HIV/AIDS Related Issues Which Haunt the Church,” *Journal of Pastoral Care* 49, no. 2 (summer 1995): 201.

<sup>39</sup> Ibid.

epidemic. The United Church of Christ issued a statement similar to that of the National Council of Churches several months following NCC's first statement. In the summer of 1983, the Universal Fellowship of Metropolitan Community Churches held a conference in Toronto and resolved that AIDS would become a priority for them at every level of the institution.<sup>40</sup> In contrast, the Roman Catholic Church tended, at first, to respond locally to the crisis. For example, in 1984, the Diocese of San Jose in California, called for special compassion in responding to persons with AIDS, their families and friends. Finally, another religious group which weighed in before 1986 included the Union of American Hebrew Congregations, representing Reform Jews. This religious group called for increased funding for research and an end to discrimination against those living with AIDS.<sup>41</sup>

In its General Convention in Anaheim in 1985, the Episcopal Church adopted a four-part program in response to AIDS. It included

- the development of special intercessory prayers for those affected by the AIDS crisis
- the development and funding of programs of awareness, education and prevention concerning AIDS;
- the identification and funding of programs of ministry to all persons affected by AIDS, and

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<sup>40</sup> Ibid., xiv. The stance of the Metropolitan Community Churches follows from the fact that its membership is predominantly made up of gay men and lesbian women. The MCC churches sustained heavy losses to AIDS. For the effects of AIDS on the San Francisco Metropolitan Community Church, see Kittredge Cherry and James Mitulski, "We Are the Church Alive," in *The Church with AIDS: Renewal in the Midst of Crisis*, ed. Letty M. Russell (Louisville: Westminster/John Knox Press, 1990) 163-74.

<sup>41</sup> Further research is needed to explore the factors that stimulated some churches to respond earlier to the threat of AIDS, in contrast to the far greater number that responded more slowly.

- the implementation of these programs by appropriate programs, units of the dioceses, parishes and missions of the church.<sup>42</sup>

Facts about the transmission of AIDS accumulated slowly at first. The publication of the Surgeon General's Report on AIDS in 1986, however, constituted a watershed event. This report clearly described the viral nature of AIDS, the lack of a known cure, the dangers of AIDS, the dominant means of transmission, and tactics for prevention, including condoms for individuals in high risk groups and sterilized needles for injection drug users. This report predicted an anticipated sharp rise in the number of AIDS deaths, and suggested that women and children, as well as men, would constitute an increasingly large proportion of those infected with the virus causing AIDS.

As J. Gordon Melton noted, with the publication of this report, church leaders began to break their silence on the issue and many denominations began to publish statements for their members. However, the churches' silence on the issue of AIDS in the early years of the epidemic failed to counter successfully the harsh statements made by conservative Christian spokespersons. Thus, they contributed to the political delay in the nation's response to AIDS and the increased stigma associated with the illness.

#### Factors Inhibiting the Churches' AIDS Ministry

The factor that most crippled churches in responding compassionately to the AIDS crisis was the association of AIDS with gays and lesbians. It is difficult, some twenty years into the epidemic, to recapture fully the degree of dis-ease and hatred that characterized the response of certain religious leaders to gays and lesbians in the early eighties. When it was first identified, AIDS was described as a "gay disease," and many

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<sup>42</sup> B. J. Stiles, "AIDS and the Churches: Belated, Growing Response," *Christianity and Crisis* 45, no. 22 (13 January 1986): 534-46.

eighties. When it was first identified, AIDS was described as a “gay disease,” and many “considered it appropriate punishment for men who violated natural law.”<sup>43</sup>

Unfortunately, the views of religious conservatives had an undue influence on President Ronald Reagan and the U.S. government during this period. The long term effect of this influence was official silence on AIDS and a lack of funding for research on prevention and treatment, a stance which contributed greatly to loss of lives. The 1983 statement of Ronald S. Godwin, an executive of the Moral Majority, exemplified the opposition of leaders of the religious right to government funding for research and treatment. He stated. “What I see is a commitment to spend our tax dollars on research to allow these diseased homosexuals to go back to their perverted practices without any standards of accountability.”<sup>44</sup> It is difficult to assess the effect that such statements had on the public climate; however, the record clearly documents public disregard for gay men and drug users and extremely slow governmental response to the threat of AIDS in the first years of the epidemic. These political failures, influenced by the statements of conservative religious leaders, were matched by corresponding social failures. As Shelp and Sutherland note:

Public disregard for gay men took the form of indifference to a major emerging threat to public health, probably to the public’s peril. Prejudice toward people who engaged in risky practices . . . joined with public fears of contagion to foster hysteria and panic.<sup>45</sup>

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<sup>43</sup> Earl E. Shelp and Ronald H. Sunderland, *AIDS and the Church: The Second Decade*, rev. ed. (Louisville: Westminster John Knox Press, 1992), 19.

<sup>44</sup> Ibid.

<sup>45</sup> Ibid., 21.

As a result, people with AIDS were fired from jobs, evicted from their apartments, denied medical insurance benefits, and deserted and abandoned by friends and families. Funeral directors refused to handle their bodies and health care professionals declined to provide medical services. Children with AIDS were sent home from schools and people were told by the press to avoid contact with “stereotyped gay service providers” including hairdressers, florists, designers and waiters.<sup>46</sup>

Even as late as 1985, gay men continued to be treated as scapegoats in the political arena. In Houston, Texas, mayoral candidate Louie Welch announced a four-point plan to control AIDS, one of which was to “shoot the queers.”<sup>47</sup> In 1985, White House Director of Communications, Pat Buchanan, described AIDS as “nature’s retribution, God’s will, paying the piper, [or] ecological kickback . . .”<sup>48</sup> Finally, in California in 1986, Lyndon LaRouche and the “Prevent AIDS Now Initiative Committee” (PANIC) placed a proposition on the ballot that could have barred infected people from certain jobs, mandated reporting infected persons to state health authorities and possibly sanctioned quarantining persons with AIDS or people who [were] well but infected.”<sup>49</sup>

In the light of these very public actions, it is difficult to understand fully the relative silence of the churches during the early years of the epidemic. Six factors, however, undoubtedly contributed to the churches’ failures. The first, already noted, was

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<sup>46</sup> Ibid.

<sup>47</sup> Ibid.

<sup>48</sup> Ibid., 22

<sup>49</sup> Ibid., 23. Welch lost the 1985 election. Proposition 64 was ultimately defeated at the polls by a 4-1 margin. See Patrick Runkle, “Proposition 22 Causes Ballet Box Deja Vu,” [on-line]; accessed 6 March 2001; available from [www.journalism.berkeley.edu/chavez/runkleb.htm](http://www.journalism.berkeley.edu/chavez/runkleb.htm).

homophobia. In September 1985, Domenic Cianella, rector of Holy Trinity Parish in Hicksville, New York, a Long Island parish, wrote about his church's failure to continue a ministry to gays and lesbians that had begun in the Fall of 1979. The ministry failed because it lacked "the blessing of the bishop, the venturesomeness of the press, the support of the clergy, the prayers of the people and the acceptance of believers."<sup>50</sup>

Through his experience, Cianella learned:

The church is a house of prayer for all people, but not yet. All are included but not yet. All are welcome, but not yet. All are made worthy by Christ, but some must change. All are sinners, but some more than others. All are Christbearers – but some are unnatural.<sup>51</sup>

These words, written in anguish nearly sixteen years ago, still describe the stance of many in the Episcopal Church, a church which even now refuses to endorse officially the blessing of same sex unions and the ordination of gays and lesbians.

Other factors contributing to the churches' failure to minister effectively in the AIDS crisis included fear of drugs and the drug culture and racism. As William Swing, Episcopal Bishop of California, wrote in 1988, "the wrong kinds of people . . . are dying with AIDS. Only this reality explains the church's response to the epidemic. Before the church could arouse itself to a Christ-like response, it stumbled into self-righteousness."<sup>52</sup>

The adoption of the works-righteousness heresy was perhaps the dominant theological factor that lay beneath the Christian church's slow and inadequate response to

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<sup>50</sup> Domenic K. Ciannella, "Requiem for an AIDS Victim," *The Witness*, September 1985, 11.

<sup>51</sup> Ibid.

<sup>52</sup> William Edwin Swing, "Silence in the Sanctuaries," *Christianity and Crisis* 48 (4 July 1988): 225.

AIDS. As L. William Countryman stated in his March, 1986 address on the AIDS crisis at a national conference of the Episcopal Church in San Francisco,

You cannot make things go right for you by being good . . . What is more, you cannot even make them go right by repenting . . . God's grace is not dependent on your goodness. And if the good gifts don't depend on your goodness, the inevitable corollary is that the affliction is no index of your badness. Those who would maintain otherwise are flying in the face of the gospel and of the faith of the church, Catholic and Reformed.<sup>53</sup>

Thus, the view that gay men and drug users "deserved" their infection as punishment for sin denied the love and grace of God. In concluding his theological reflection on AIDS, Countryman asked, "How can it be in accord with the Gospel to believe in a God who would sacrifice his only child on the cross in order to replace one set of regulations with another, one set of pigeonholes with another? If that God is true, the teaching of Jesus is false."<sup>54</sup>

Other fears, besides the fear of difference, contributed to the churches' failure. One fear in particular-- the fear of death -- arose from the churches' captivity to culture. In a thoughtful reflection on the AIDS crisis, John Snow, Professor of Pastoral Theology at the Episcopal Divinity School, identified "the survival of the fittest" as a dominant cultural ethos. He noted, on the one hand, that a prophetic church would concentrate on saving the national leadership from a demonic world view, reflected in the belief that "the human enterprise is best served by the material aggrandizement of the self, motivated by the fear of death."<sup>55</sup> On the other hand, he observed that the church seemed to be

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<sup>53</sup> L. William Countryman, "The AIDS Crisis: Theological and Ethical Reflections," *Anglican Theological Review* 69, no. 2 (April 1987): 127.

<sup>54</sup> *Ibid.*, 127.

<sup>55</sup> John Snow, "AIDS and 'The Survival of the Fittest,'" *The Witness* 72, December 1989, 23.



characterized as much by competition as any other strata of society. In his opinion, the church, faced with AIDS, lacked both the motivation and vision to preach the gospel. The antidote, he stated, was a radical encounter with death, a movement to the margins where the church could recover the values and virtues essential to Christianity. Presiding Bishop Edmond Browning of the Episcopal Church, writing in 1987, also described the spiritual challenges that arose in the face of AIDS deaths. As he noted, "it is hard not to be spiritually shaken in the face of [difficult] questions. It is so much easier to focus on fighting AIDS on scientific, secular turf or, on supposedly moral grounds, to blame its victims."<sup>56</sup> In other words, it was easier to avoid the difficult theological and spiritual questions AIDS raised than it was to trust in God's loving care for humanity and all creation. The AIDS epidemic exposed the churches' own lack of faith.

A final factor contributing to the churches' slow response to AIDS was the fear of sexuality. The fear of sexuality seems long established in the Christian tradition, a tradition that has been deeply suspicious of pleasure and passion. Greek and Gnostic dualisms contrary to the body have plagued Christianity for centuries. Further, dualism has contributed to an identification of women with sexuality and a projection upon them of a suspicion and even hatred of their sexual energy. These dynamics, according to John McNeill, are also responsible for homophobia. He states, "that it is the same age-old tradition of male control, domination, and oppression of women which underlies the oppression of the homosexual."<sup>57</sup> The coming of AIDS has served to highlight the

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<sup>56</sup> Edmond L. Browning, "The Spiritual Challenge," *One World*, December 1987, 9.

<sup>57</sup> John McNeill, *The Church and the Homosexual* (Kansas City: Sheed, Andrews & McMeel, 1976), 189.

inadequacy of the Christian church's sexual theology and the inadequacy of our theological and sexual ethics has magnified the suffering of persons with AIDS.

In conclusion, the inability of most churches in the United States to adopt a compassionate stand in the early days of the AIDS epidemic fostered a political and social climate that prolonged the epidemic and increased the suffering of persons with AIDS. As the epidemic has continued, churches of all sorts --including liberal, evangelical and African American Christian churches -- have continued to deny the full impact of the suffering associated with AIDS in the United States and abroad.<sup>58</sup> Six factors contributing to these trends have been identified. They include: homophobia, fear of the drug culture, racism, works righteousness, fear of death, and fear of sexuality. In a later chapter, theological reconstructions will be offered that may pave the way for a more adequate response.

### Conclusion

This review has revealed several aspects of the problem of AIDS and AIDS loss that are significant to this work. First, we have confronted the magnitude of infection and loss in San Francisco and around the world. The staggering numbers of persons living with HIV/AIDS and of those who have died suggest an enormous burden of grief. The

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<sup>58</sup> For the effect of AIDS on liberal churches see J. Gordon Melton, *The Churches Speak on AIDS and Facing AIDS: The Challenge, The Churches' Response*. WCC Study Document (Geneva: WCC Publications, 1997). For the evangelical churches, see Ayers, "Quagmire of HIV/AIDS Related Issues." For the effect of AIDS on the Roman Catholic Church see Mark R. Kowalewski, *All Things to All People: The Catholic Church Confronts the AIDS Crisis* (Albany: State University of New York Press, 1994); and Richard L. Smith, *AIDS, Gays and the American Catholic Church* (Cleveland: Pilgrim Press, 1994). For the effects of AIDS on the African American Church see Ronald Jeffrey Weatherford and Carole Boston Weatherford, *Somebody's Knocking at Your Door: AIDS and the African-American Church* (Binghamton, N.Y.: The Haworth Pastoral Press, 1999.) Finally, for an account of the effect of AIDS on a Jewish synagogue in New York City see Moshe Shokeid, *A Gay Synagogue in New York* (New York: Columbia University Press, 1995).

loss of human potential that may be attributed to AIDS cries out for effective strategies for prevention. At the same time, it suggests the need to address the burden of bereavement that many bear. Particularly pressing are the needs of those who live with the double pain of infection and loss. My hope is to begin to address the “death in life” that bereavement can represent.

Second, social analysis suggests that different populations may require different strategies for prevention and support. At the core of effective care, however, is an emphasis on human dignity and empowerment that is healing in itself.

The political analysis of AIDS underscores the need for honesty and courage in confronting the epidemic and its patterns of devastation and loss. We cannot automatically assume that those at greatest risk have access to needed resources. In fact, the opposite is true – those at greatest risk have least access to resources, at least within developing countries. Thus, advocacy remains an important priority in response to HIV/AIDS.

Finally, exploration of the religious aspects of AIDS points out the relationship between religious, social and political conservatism. This relationship highlights the need for the Christian churches to formulate a more adequate theological response to the challenges posed by AIDS, so that society’s care may be extended most generously to those in need and scapegoating can be eliminated.

With these results in mind, let us now turn to a further nuancing of the problem.

## CHAPTER 3

### “GEOGRAPHY OF THE HEART”: PSYCHOLOGICAL ASPECTS OF AIDS LOSS

On a discouraging night not long after Larry's death, I wrote my next-older sister who had herself helped a lover through his death from leukemia. “Tell me, O older and wiser sister,” I wrote, “how long will this grief last?” Older and wiser, she wrote back: “Grief is never over. The time will come when you control your grief rather than the other way around. You'll draw upon those memories when you need and want them, rather than having them show up uninvited. But your grief will never go away, which is the way it should be. It and Larry are part of who you are.”<sup>1</sup>

. . . [T]he one thing I can say is that there is no way I could convey, in any way, the depth of feeling that has gone through my heart, the *incredible sense of so much loss*, in such a . . . short space of time. Some people have said it's like a war.<sup>2</sup>

The psychologist John Martin and his associate Laura Dean performed some of the earliest and best psychological research on the effects of AIDS-related loss on gay men in New York City. Tragically, John Martin himself was to die of AIDS in 1992. Before his death, however, he and his associates clearly identified a number of the main issues that continue to influence psychological treatments of the effects of AIDS loss. In his earliest work, for example, Martin hinted at the potential inadequacy of existing bereavement theories, based as they were on conjugal loss or parental loss, to account for the bereavement experience of gay men in the AIDS epidemic.<sup>3</sup> Further, Martin

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<sup>1</sup> Fenton Johnson, *Geography of the Heart: A Memoir* (New York: Scribner, 1996), 210.

<sup>2</sup> Gregory Neil Shrader, “A Descriptive Study of the Effects of Continuous Multiple AIDS-Related Losses among Gay Male Survivors” (Ph.D. diss., California School of Professional Psychology, Los Angeles, 1992), 91.

<sup>3</sup> John L. Martin, “Psychological Consequences of AIDS-Related Bereavement among Gay Men,” *Journal of Consulting and Clinical Psychology* 56, no. 6 (1988): 856.

suggested that grief resulting from multiple AIDS losses might lead to different patterns of distress and vulnerability to illness than grief resulting from single losses. Beginning in his first study, therefore, Martin attempted to delineate potentially unique and characteristic patterns associated with AIDS loss. In addition, he attempted to determine whether gay men appeared to habituate to loss over time. As we shall see in this chapter, the foundation Martin laid in his groundbreaking work set the stage well for all subsequent research on the psychological aspects of AIDS loss.

Martin's earliest results, based on interviews conducted in 1985 with gay men in New York City, found a direct relationship between the number of AIDS losses sustained and symptoms of traumatic stress response, demoralization, sleep problems, sedative use, recreational drug use and the use of psychological services because of AIDS concerns. A second longitudinal study, based on repeated interviews conducted between 1985 and 1991 with the same sample, replicated many of the original findings. That is, bereavement continued to exact a psychological toll on Martin's gay subjects, as bereavement was associated with depression, traumatic stress, sedative use and suicidal ideation. However, an additional, notable finding emerged: the occurrence and duration of bereavement effects appeared to diminish over time in HIV-negative men, whereas HIV-positive men or men with AIDS continued to experience high levels of distress.<sup>4</sup>

Martin's foundational research, therefore, points out the need to understand the psychological effects of AIDS loss *contextually*. In an equally thorough treatment of

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<sup>4</sup> John L. Martin and Laura Dean, "Effects of AIDS-Related Bereavement and HIV-Related Illness on Psychological Distress among Gay Men: A 7-Year Longitudinal Study, 1985-1991," *Journal of Consulting and Clinical Psychology* 61, no. 1 (1993): 94-103.

AIDS-related loss, Peter Goldblum and Sarah Erikson develop a helpful schemata for exploring the many-faceted psychological aspects of AIDS-related loss. I shall rely on their approach here to outline major aspects of the psychology of AIDS loss as they are developing in the increasingly vast literature devoted to the subject.

### **The Contextualization of AIDS Loss: Five Key Aspects**

Like Martin and his associates, Goldblum and Erikson mention the need to explore the contextualization of the experience of AIDS loss.<sup>5</sup> In their treatment of this subject, they explore the effects of four sets of variables: (1) the history of the epidemic, (2) the cultural context of mourning, (3) the search for personal meaning in AIDS loss and (4) the psychology of grief. I have found that a fifth variable, the mourner's HIV status, may also have a dramatic effect on the psychological experience of AIDS loss, and thus, it also provides an important contextual variable.

#### **History of the Epidemic**

Understanding the history of the epidemic, the first contextual factor, is important because it contributes to an appreciation for the uniqueness of AIDS loss. As we have already noted, because the epidemic was first associated with marginalized and stigmatized groups, including gay men and hemophiliacs, the general public initially perceived little threat from AIDS and the government provided few funds for public research. Over time, awareness of the global threat of AIDS grew, in addition to the knowledge that the disease could be transmitted heterosexually. However, even today, AIDS continues to be a disease located primarily in urban centers in the United States

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<sup>5</sup> Peter B. Goldblum and Sarah Erickson, *Working with AIDS Bereavement: A Comprehensive Approach for Mental Health Providers*, UCSF AIDS Health Project, Monograph Series, 3 (San Francisco: University of California, San Francisco 1999).

among gay and bisexual men, intravenous drug users and their partners, and people of color. The distribution of AIDS raises two issues related to care: first, people experiencing AIDS loss in small towns and rural areas in the United States frequently have access to fewer supportive services. Second, individuals in the particular population groups at greatest risk of infection tend to experience chronic loss. As Goldblum and Erikson note:

As of 1994, 60 percent of gay men were losing at least one person a year to AIDS, and one-third of these bereaved individuals described multiple loss of family, friends and neighbors. This presents individuals in groups hardest hit by the epidemic with a dilemma: on one hand, being active in these communities can provide individuals with support in facing the epidemic; on the other hand, such community integration increases the risk that the individual will experience multiple loss.<sup>6</sup>

In assessing the psychological effects of AIDS loss, it is important to know where a mourner resides and whether he or she is a member of a high risk group and thus susceptible to repeated losses.

Understanding the history of the epidemic and the association of AIDS with marginalized groups also increases awareness of the considerable stigma that may accompany the experience of AIDS loss. Research comparing mourners whose losses result from AIDS versus those with losses from cancer demonstrates that AIDS mourners reported lower levels of social support in response to bereavement, had experienced more losses, reported more support from friends than family and were more likely to hide the cause of death from others.

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<sup>6</sup> Ibid., 8

Finally, familiarity with the history of the epidemic suggests that those experiencing losses from HIV and AIDS are more likely to be young themselves and to have experienced the death of young friends. This factor may place them at greater risk for prolonged or pathological grief. Another factor placing AIDS mourners at risk is that many of them are likely to have been either caretakers or HIV-positive themselves, factors which further contribute to the likelihood of complicated grief, stigmatization and isolation.<sup>7</sup>

#### Cultural Factors

A second factor shaping the context of grief is culture. Understanding cultural factors in bereavement provides an appreciation both for the normative treatment of death in the United States and for an important basis for deviation from it. According to Kathy Charmatz, death in the United States tends to be treated as a problem requiring solutions.<sup>8</sup> The solutions are understood to be technical, requiring either medical or psychotherapeutic interventions. One implication of this view is that death itself can be understood as failure in a culture that emphasizes individual achievement, self sufficiency, privatism and hard work. Further, the individualism and mobility of our culture and the concentration of mourners in nuclear families often limits the availability of emotional support in grief. The isolation of many mourners in the United States may prolong the grieving process.

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<sup>7</sup> Ibid., 9

<sup>8</sup> Kathy Charmatz, *The Social Reality of Death* (Reading, Mass.: Addison-Wesley Publishing, 1980); cited in Goldblum and Erickson, *Working with AIDS Bereavement*, 10.



Ethnographic research on AIDS bereavement highlights the effect that particular features of HIV disease may have on the cultural experience of mourning. In Uganda, the work of Seeley and Kajura suggests that the prevalence of AIDS deaths has decreased the period of time normally spent in mourning following a loss. The abbreviation of the mourning period is due, in part, to the financial burden multiple deaths have caused for families. Further, the stigmatization of AIDS in that country has caused Ugandans both to conceal the cause of death and to dissociate themselves from the disease when either a friend or family member has died of AIDS.<sup>9</sup> This example illustrates that it is important to understand both cultural norms associated with grieving and the ways in which HIV disease may result in their adaptation.

Understanding cultural factors affecting bereavement also suggests that such factors may have an effect on the institutions to which mourners turn for relief. For example, Larry Gant notes that African Americans affected by AIDS are less likely than gays and lesbians to use HIV services and to confront openly the issue of AIDS in their communities. He suggests two reasons for this pattern: first, African Americans may fear a loss of personal or cultural integrity and second, they may also fear the stigmatization that can follow from accessing services associated with homosexuals. One consequence of these factors is that African Americans, perhaps more than gays and lesbians, tend to

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<sup>9</sup> Janet Seeley and Ellen B. Kajura, "Grief and the community," in *Grief and AIDS*, ed. Lorraine Sherr (Chichester, England: John Wiley and Sons, 1995); cited in Goldblum and Erickson, 11-12.

rely on resources within their own communities, such as their families and churches, in coping with HIV disease.<sup>10</sup>

Finally, cultural factors may also account for certain patterns in gay and lesbian grief. It is not uncommon for gays and lesbians to experience estrangement both from their families and from religious communities. These realities, paired with the migration of many gay and lesbian people to large urban centers, may account, in part, for the rise of HIV community organizations such as the famous Gay Men's Health Crisis in New York and the San Francisco AIDS Foundation in San Francisco. Further, the development of community based rituals such as AIDS marches, candlelight vigils and memorial services spearheaded by the gay community provides gays and lesbians with resources they may use simultaneously to express their grief and to affirm their sense of community identity and pride.<sup>11</sup>

### Meaning

A third contextual factor influencing the expression of grief is the question of meaning. The experience of loss seems inevitably to be associated with questions of meaning. Mourners ask themselves such crucial questions as Why did this happen? and What effect will this loss have on my present and future life? The normal questions of meaning associated with loss tend to be exacerbated in the case of AIDS. This is due to

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<sup>10</sup> Larry Gant, "HIV/AIDS Caregivers in African-American Communities: Contemporary Issues," *Caring for the HIV/AIDS Caregiver*, ed. Vincent J. Lynch and Paul A. Wilson (Westport, Conn.: Auburn House, 1996); cited in Goldblum and Erickson, *Working with AIDS Bereavement*, 12-13.

<sup>11</sup> This point is made by Goldblum and Erickson in *Working with AIDS Bereavement*, 13-14.

several aspects of the experience, including the devastating nature of the disease, the magnitude of the loss many mourners experience, and the youthfulness of those dying with AIDS and of those sustaining losses.

Goldblum and Erickson describe the work of two researchers who focus on questions of meaning. The first, Camille Wortman, notes that mourners who cannot incorporate AIDS loss into their philosophical perspective on the world are at risk for bereavement distress. Mourners whose world view is upset by AIDS loss face one of two outcomes. Either they adopt a new world view which facilitates coping or they live permanently with the unresolved conflict generated by the loss. Individuals who are unable to reconcile themselves to the loss may “give up on the world” and hold back on relationships so as to shield themselves from further loss. Wortman indicates that two kinds of individuals are particularly at risk. The first are those who believe that the world is controllable, safe and predictable, for the experience of AIDS loss inevitably shatters those beliefs. Surprisingly, however, the second group at risk are those who have the greatest intellectual and financial resources and feelings of high self-esteem and mastery prior to the loss. For these individuals, the loss represents a devastating blow and constitutes a situation in which they experience helplessness, despite the many resources they possess.<sup>12</sup>

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<sup>12</sup> Camille B. Wortman, Roxane C. Silver, and Ronald C. Kessler, “The Meaning of Loss and Adjustment to Bereavement,” in *Handbook of Bereavement: Theory, Research and Intervention*, ed. Margaret S. Stroebe, Wolfgang Stroebe and Robert O. Hansson (Cambridge: Cambridge University Press, 1993); cited in Goldblum and Erickson, 14-15.

A second, important study focused on questions of meaning is Christopher Mead's research with young seropositive people.<sup>13</sup> This work, conducted in the Netherlands, focused on seropositive people and their caretakers who were primarily between the ages of 20 and 39. Mead suggested that these people were developmentally at risk from HIV disease. His research suggests that those he interviewed were required through their exposure to AIDS to take on the developmental tasks of old age at a time when they were unprepared for them. His findings suggest that doing so can precipitate an emotional crisis. In the absence of sufficient emotional resources, this led some participants in his study to psychological problems, including the re-emergence of conflicts related to their sexual orientation. However, his research also suggests that those with the necessary psychological resources to weather this crisis emerged from it with wisdom beyond their years.<sup>14</sup>

One of the earliest and most influential studies of AIDS-related multiple loss is the work of Gregory Neil Shrader. Shrader's phenomenologically oriented psychological study was focused, in part, on questions of meaning associated with experiencing multiple AIDS losses. Shrader conducted interviews with 15 gay men in the Los Angeles area in the early 1990s. The men in Shrader's study had lost a total of over 1,000 people to AIDS. He reports several findings directly related to questions of meaning. First, many of his interviewees derived meaning from viewing themselves as survivors. That

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<sup>13</sup> A seropositive or HIV positive person is a person whose HIV antibody test has indicated the presence of antibodies in the blood. If the test is positive, the person has been exposed to HIV and his or her immune system is developing antibodies to the virus.

<sup>14</sup> Christopher Mead, "Crisis of the Psyche: Psychotherapeutic Considerations on AIDS, Loss and Hope," in *Grief and AIDS*, ed. L. Sherr; cited in Goldblum and Erickson, *Working with AIDS Bereavement*, 19.

is, awareness of the strength and compassion that allowed them to survive the many losses associated with AIDS was a source of pride. Second, these men also reported valuing their role as witnesses to the lives of their loved ones who died. A third source of meaning arose from the increased sense of life's preciousness and beauty that accompanied the experiences of AIDS loss. Other interviewees spoke of the meaning of AIDS in relationship to gay life: on the one hand, some saw it as one source of difficulty in an already difficult lifestyle and some interviewees used the image of AIDS as a "war" within the gay community. On the other hand, other interviewees spoke of AIDS as a stimulus for increased involvement in the gay community and for re-investment in self, health and gay relationships. They also described AIDS as a catalyst for action, and men expressed pride in the community's response to the challenges posed by it.

In contrast to those who did find meaning in AIDS loss, some men felt that they could attribute no particular meaning to AIDS, saying "AIDS is just a disease" or "AIDS just *is*, there is no meaning to it" Finally, some felt that it was simply too soon to attribute deep meaning to it. Taken as a whole, Shrader's results are helpful in pointing out the wide range of responses that were associated with AIDS loss within the primarily Caucasian gay community of Los Angeles. Attending to the contextual factors associated with AIDS losses may help to nuance future findings. Why is it, for example, that some men find deep meaning in their experience of survival, whereas others appear to be numb? Further research is needed to explore these and other patterns of difference in response to AIDS loss.<sup>15</sup>

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<sup>15</sup> Shrader, "Descriptive Study of the Effects of Continuous Multiple AIDS-Related Losses."

One excellent study that attempts to explore variations in meaning-making in the wake of AIDS is the work of Steven Schwartzberg. In this work, Schwartzberg framed the AIDS crisis as a crisis of meaning and he presents a psychological framework for how HIV-positive gay men have and have not found meaning in HIV and AIDS.

Schwartzberg, a clinical psychologist, conducted clinical research interviews with 19 seropositive gay men between 1990 and 1991. His interviewees ranged in age from 27-50 years. In the analysis of his interviews, Schwartzberg identified ten main themes his interviewees used to make meaning out of the impact of HIV and AIDS. The basic “building blocks” of meaning included the following themes:

- HIV as a catalyst for personal growth
- HIV as a catalyst for spiritual growth
- HIV as belonging, as a source of deeper connection to others
- HIV as relief from the struggle of life and from coming out as a consequence of infection
- HIV as strategy, as a way of receiving attention, love or recognition
- HIV as punishment for pleasure
- HIV as contamination, either in making one deserving of stigma or in increasing the awareness of being infectious
- HIV as a confirmation of powerlessness against larger, uncontrollable forces
- HIV as isolation, as leading to a profound sense of separateness and fear of rejection
- HIV as irreparable loss due to the death of beloved people, the loss of gay cultural norms, styles of sexual expression, diminished future possibilities, or the premature relinquishment of personal hopes and fantasies.<sup>16</sup>

Schwartzberg found that his interviewees combined these themes in many ways in their attempts to make meaning following their infection with HIV. Besides identifying these themes, Schwartzberg also described four styles that characterized adaptation to

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<sup>16</sup> Steven Schwartzberg, *Crisis of Meaning*, 40-67.

HIV in the men he interviewed. These styles serve as descriptors for the varying ways that men in his study integrated HIV and AIDS into their life's meaning.

The first style Schwartzberg describes is "transformation."<sup>17</sup> Men who adopt this style successfully convert the challenges of HIV into a fuller appreciation of life.

Schwartzberg describes a number of characteristics of men who adopt a transformational style. In general,

- they believe they have the power and responsibility to shape the meaning of their lives, including their HIV infection
- they fully admit the reality of their infection but are able to maintain some distance from AIDS
- they have discovered something in facing AIDS or HIV that unlocks a special quality within them
- they feel a sense of kinship with other gay or HIV-positive men
- they are more focused in the here and now
- they believe in an afterlife or in some other ongoing symbolic existence
- they behave altruistically, and
- they can tolerate the paradox, and the tension, of contradictory beliefs and feelings regarding HIV and AIDS.<sup>18</sup>

Schwartzberg believes that this style is the most adaptive of the four he identified.

The second style Schwartzberg describes is "rupture."<sup>19</sup> A primary determinant for the adoption of this style appears to be the presence of unresolved grief. This style is characteristic of men whose lives appear to be shattered by AIDS. It occurs in men for whom AIDS disrupts their prior framework for making meaning and who seem unable to create a new framework of meaning. Men with this style tended to experience significant depression, anxiety, bitterness, feelings of disempowerment and fear.

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<sup>17</sup> Ibid., 71-100.

<sup>18</sup> Ibid., 83

<sup>19</sup> Ibid., 101-24.

“Camouflage” is the third style Schwartzberg describes.<sup>20</sup> Men with this style displayed a tenuous integration of HIV into a new framework for life’s meaning. In general, men adopting this style tended to hide their true feelings about HIV from themselves and others.

The final style Schwartzberg describes is “impassivity.”<sup>21</sup> Some HIV positive men Schwartzberg interviewed appeared to be indifferent to the effects of HIV. He notes that infection simply did not appear to be a prominent part of their identity. In describing this style, Schwartzberg highlights the fact that “*Not everyone needs to go through great crisis to cope effectively with trauma.*”<sup>22</sup> For some men, this style appears to be the most adaptive way of coping with the reality of HIV/AIDS, as surprising as this may seem.

A final contribution arising from Schwartzberg’s excellent study is his analysis of the ways in which his interviewees attempted to tolerate or reduce the uncertainty that was associated with an HIV positive diagnosis in the early 1990s. Schwartzberg identified five main ways in which the men coped with the general uncertainty of their situation. Each represented a way of attempting to gain greater control. First, the men decided who it was that had infected them. Second, almost all of them used easy, round numbers to estimate a period of remaining health, such as “five years” or “ten years,” or they chose particular milestones, such as their fortieth birthday, as goals. A third strategy they adopted was to maintain contact with persons with AIDS as a way of anticipating the

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<sup>20</sup> Ibid., 125-46.

<sup>21</sup> Ibid., 147-70.

<sup>22</sup> Ibid., 159 (original emphasis).



effects of their infection. Fourth, the men he interviewed tended to predict that they would develop AIDS as a way of turning an uncertain future into a more concrete one. Finally, the men in his study tended to think about death. In general, they kept a necessary distance from it and thought of it in abstract terms, but they were concerned with it nonetheless. Many men developed a “mixed style,” relying on more than one of these coping strategies.

Schwartzberg’s research provides a strong contribution to the psychological literature on HIV/AIDs and meaning. He captures the flavor of varying responses to the HIV-positive diagnosis. A challenge for future researchers is to study what effect the advent of antiretroviral medications has had on the styles of meaning-making he identified, since many HIV-positive individuals now face a much brighter future than Schwartzberg’s interviewees did in the early 1990s.

### The Psychology of Grief

According to Peter Goldblum and Sarah Erickson, a fourth contextual factor influencing the understanding and expression of grief is the psychology of grief. Theorists have defined the psychological response to grief variously. As these authors note, psychological theories concerned with grief have, however, tended to be of two types. Either they have a psychodynamic emphasis and focus on the underlying conscious and unconscious processes that mediate grief or they have a cognitive and behavioral emphasis and focus on factors related to stress and coping that affect bereavement distress. In their work, Goldblum and Erickson draw on aspects of both types of theories, seeking to develop an integrative model of AIDS bereavement.

A number of theorists have advanced psychodynamic theories of grief, and each has offered helpful distinctions. Sigmund Freud, who described the grieving process in his classic article on the subject, "Mourning and Melancholia," distinguished normal bereavement from depression.<sup>23</sup> The major difference between them is that depression is accompanied by a marked diminution in self-regard, whereas bereavement is not. John Bowlby's classic work on bereavement in the 1960s is based on research with young primates and children.<sup>24</sup> Bowlby's model of bereavement is based on the development of attachment to a primary caretaker, and he describes the consequences of separation and loss. In formulating his theory, he draws on psychoanalytic theory, ethology, control theory, cognitive psychology and cybernetics. Bowlby offers a four stage notion of bereavement, in which mourners pass through shock and numbing, yearning and searching, disorganization and despair and efforts toward reorganization. William Worden also emphasizes the notion of attachment, but in developing his theory, he relied heavily on empirical studies of spousal bereavement. In contrast to Bowlby, who speaks in terms of phases of grief, Worden describes a series of tasks that must be navigated successfully by mourners. These include:

- accepting the reality of the loss
- experiencing the pain of grief
- adjusting to an environment in which the deceased is missing, and
- withdrawing emotional energy and investing it in another relationship<sup>25</sup>

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<sup>23</sup> Sigmund Freud, "Mourning and Melancholia," in *The Standard Edition of the Complete Psychological Works of Sigmund Freud*, ed. James Strachey, vol. 14 (London: Hogarth Press, 1958), 239-58.

<sup>24</sup> Bowlby's monumental work may be found in three volumes. See John Bowlby, *Attachment and Loss*, vol. 1, *Attachment* (New York: Basic, 1969); vol. 2, *Attachment and Loss* (Harmondsworth, England: Penguin, 1975); and vol. 3, *Loss, Sadness and Depression* (New York: Basic, 1980).

<sup>25</sup> See J. William Worden *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*, 2<sup>nd</sup> ed. (New York: Springer Publishing, 1991), 10-18.

As Goldblum and Erickson note, descriptions both of phases and tasks of grief are conceptually useful, since the process of mourning does not follow a specific timetable. In fact, the period of mourning varies widely as a function of the cultural context. Since time, in and of itself, does not clearly predict the progression from mourning to resolution of mourning, both Bowlby's and Worden's theories provide us with a means of assessing the grief reaction of specific mourners.

Goldblum and Erikson describe a final psychodynamic theory, namely the work of Mardi Horowitz. Horowitz' approach is grounded in theories of stress and trauma; its usefulness resides in the descriptions she provides of the psychological dynamics of mourning. In describing these dynamics, it is important to note that Horowitz draws on cognitive theory in addition to psychodynamic theory. For example, she describes the necessity for mourners to revise their *person schemata* or view of themselves and others. This is because the loss of loved ones brings with it changes in the way one understands oneself, relates to others, and plans for the future. For example, in adapting to the loss of a partner, one often must take on new roles that formerly were assumed by the loved one, such as budgeting, investing, cooking, household care or child care. These changes create new possibilities for interaction with others and may alter one's self image and the course of one's present and future life in a number of important ways. Perhaps the major contribution of Horowitz' theory, however, resides in her characterization of the mourning process as "a vacillation between times of cognitive and emotional intrusion and times of psychological suppression of these disturbing thoughts and emotions."<sup>26</sup>

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<sup>26</sup> Goldblum and Erickson, *Working with AIDS Bereavement*, 26.

This characterization of grief is helpful, because it provides a way of understanding difficulties in bereavement. They often result from extremes: either from being overwhelmed by thoughts and feelings or from suppressing them to the point of psychic numbing. Horowitz describes five phases of the mourning process: outcry, denial, intrusion, working-through and completion. As Goldblum and Erickson note, "This model helps clinicians understand the underlying mechanisms of grief, and better differentiates normal grief from its complications."<sup>27</sup>

Coping theories, in contrast to psychodynamic theories of grief, focus more on the stressors endured by mourners and the cognitive and behavioral strategies they adopt for managing them. Susan Folkman and her associates at the University of California at San Francisco have offered an AIDS bereavement theory that focuses on coping as an aspect of mourning. Two processes are important in this theory. The first is appraisal, a cognitive evaluative process in which the individual assesses the potential for his or her well-being in particular events or situations. The second process, coping, is adopted to manage the perceived stresses identified in the appraisal. Folkman and her associates have studied 314 gay men in the UCSF coping project, 61 HIV positive men paired with healthy partners and 253 men who were caregiving partners of men with HIV disease. Through their research, they identified two major sources leading to bereavement distress. The first consist of bereavement burdens. These include such things as being HIV- positive, a caretaker, or a parent of the deceased. The second source of bereavement distress is the possession of inadequate coping skills. We shall return to

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<sup>27</sup> Ibid., 27.

these two factors in the description of Goldblum and Erikson's integrative model of AIDS bereavement.

### The HIV Status of Mourners

The final contextual factor influencing the expression of grief is the mourner's HIV status. Goldblum and Erickson consider being HIV-positive to be a bereavement burden, a stressor placing demands on a mourner. However, I would argue that HIV status is a primary determinant in shaping a person's entire reaction to HIV disease and AIDS loss and not simply a factor influencing bereavement. Data to support this conclusion come from three sources: Martin's early work cited above, interviews with members of All Saints Church, and Odets' work with HIV-negative men. First, Martin found that, by 1991, men with AIDS experienced higher distress with bereavement than HIV-negative men. Second, differences emerged in my empirical research between HIV-positive and HIV-negative gay men. The HIV-positive individuals in my sample appeared to place the primary focus on managing their illness; processing their losses appeared to take second place to their concerns with health and treatment. Yet, despite this focus, their bereavement was considerable. Third, Odets documents the unique struggles that HIV-negative men have had with survivor guilt, a struggle that is made all the more poignant by the fact that both society and the gay community have tended to deny the psychological effects of the epidemic on HIV-negative men. For many years, the emotional needs of negative men were seen as secondary to those of HIV-positive men. As Odets notes, "Feelings about oneself seemed the exclusive right of those who were infected, sick, or dying, particularly if the feelings were going to demand time or

resources.”<sup>28</sup> Further, Odets describes the particular struggles that HIV-negative men have with survivor guilt:

If an individual feels ambivalence or guilt for having simply survived those dead from AIDS, imagine how impossible it will be to think and talk about the kinds of feelings now seen routinely in uninfected men: that they are depressed, anxious and lonely in their “wellness”; they are having a hard time surviving, and for many, survival is so difficult they sometimes wish they had not survived and sometimes hope that they will not. Despite the contribution of survivor guilt to often disabling anxiety and depression and, in complex ways, to unprotected sex -- such feelings are difficult to think and talk about, and are virtually impossible to ask for help with in the middle of a disaster like the epidemic.<sup>29</sup>

Odets, therefore, emphasizes the existence of psychological distress in HIV-negative men and, also, their frequent reluctance to draw attention to their need for help.

Odets describes the prevalence of bereavement distress in HIV-negative men as a “psychological epidemic.” Psychological concomitants of loss in HIV-negative men include depression, manic responses, anxiety, hypochondriasis and sexual dysfunction. His research demonstrates the importance of attending to the HIV status of mourners, as the issues facing HIV-negative and HIV-positive men in their loss do differ. For example, HIV-negative men frequently face a situation akin to “coming out” in the gay community with the disclosure of their negative status:

. . .the struggle to make sense of an HIV-negative life has many parallels to the struggle of an adolescent who is trying to be homosexual. Both are struggles with a difficult, diffuse, and conflicting internal experience that require societal recognition to be successfully consolidated as an identity. Both being uninfected and being homosexual require a coming-out process that is the more or less coordinated consolidation of internal experience and societal acknowledgement of who one is and how one feels. That being uninfected is a socially unsupported --and usually unrecognized --

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<sup>28</sup> Walt Odets *In the Shadow of the Epidemic: Being HIV Negative in the Age of AIDS* (Durham: Duke University Press, 1995), 16.

<sup>29</sup> *Ibid.*, 17.

condition is evident. . . .<sup>30</sup>

According to Odets, being HIV-negative in the 1990s resulted in a three to one ratio of crisis responses in centers providing HIV-antibody testing. That is, men receiving an HIV-negative result were three times more likely to need psychological support.<sup>31</sup> This paradoxical finding underscores the power of survivor guilt as a psychological dynamic in the AIDS epidemic in the gay community.

In summary, therefore, we have seen the important influence that five contextual factors -- the history of the epidemic, the cultural context of mourning, the search for personal meaning, the psychology of grief and HIV status -- may have on shaping the experience of AIDS loss. Awareness of each of these factors provides important information about a particular individual or community's experience of loss. AIDS loss varies across time, group and location; attending to the contextual variables identified in this chapter allows caregivers to nuance their understanding of and response to people experiencing psychological distress from AIDS bereavement.

### **AIDS Loss as Multiple Loss**

In this overview of contextual variables shaping the experience of AIDS loss, I have described several aspects of this loss that make it unique. One of the most important attributes of AIDS loss, however, is that, for most mourners, AIDS loss is actually an experience of multiple loss. To a certain extent, any loss can be understood as multiple loss. Besides the loss of a particular loved one, for example, any mourner experiences the loss of various functions performed by the deceased and the loss of memory and identity

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<sup>30</sup> Ibid., 119.

<sup>31</sup> Ibid., 45.

associated with him or her. A number of factors, however, combine to intensify the character of AIDS loss as multiple loss.

The first factor is the concentration of AIDS losses in particular communities. We have already alluded to this fact in our treatment of the epidemic's history. For the sake of this discussion, it is important simply to note that AIDS losses are not distributed randomly throughout the population. The groups at greatest risk of experiencing AIDS loss in the United States include gay and bisexual men; intravenous drug users and their partners and children; hemophiliacs; and, increasingly, African Americans and Latinos living in major urban centers. In addition, the number of losses experienced in these communities has mounted steadily over time, although the rate of acceleration has decreased with the advent of new treatments. The following statistics, however, provide some concrete support for the increasing magnitude of loss:

Among a panel of New York gay men in 1987, each person reported an average loss of 6.7 people to AIDS . . . In 1991, Boykin estimated an average range of 8-16. Shrader's (1992) study targeted at gay survivors of multiple loss showed a mean loss of 67.7 persons to AIDS.<sup>32</sup>

Besides experiencing great *numbers* of losses, individuals living in communities heavily affected by AIDS have sustained many *types* of losses. According to Nord, these include:

- the loss of family, lovers, friends and acquaintances
- the loss of personal history
- the loss of hopes and dreams
- the loss of security
- the loss of emotional well-being
- the loss of interest and pleasure in life

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<sup>32</sup> Nord, *Multiple AIDS-Related Loss*, 45.



- the loss of self esteem (secondary to a feeling of contagion)
- the loss of roles
- the loss of spirituality, meaning and assumptions
- the loss of privacy, when coming out becomes associated with seeking support or caring for friends and partners who are sick
- the loss of community, and
- the loss of celebration and sexual freedom<sup>33</sup>

Recognizing the nature of AIDS loss as multiple loss appears to be important for two reasons. First, it highlights the inadequacy of many existing theories for describing the course of mourning, and second it points to the need for a careful description of the unique effects of this form of loss. Shrader eloquently describes the difficulty facing many existing theories of grief in accounting for AIDS-related multiple loss:

[the theories] are simply inadequate for describing any multiple loss experience, in general, let alone multiple AIDS losses. Specifically, what they define as “pathological grieving” resulting from one significant loss may actually be the “norm” for grieving multiple losses. . . [Further], these theories do not take into account the influence of the politics, stigmatization and other stressors that relate to the grieving of multiple AIDS-related losses.<sup>34</sup>

Shrader also makes the very important point that psychological theories of grieving, when applied to survivors of AIDS loss, tend to emphasize the difficulties facing them rather than emphasizing the strength that has allowed them to survive. As he notes:

to look solely at the difficulties these men face and not to mention the incredible strength and remarkable coping that so many of the subjects exhibited, is to pathologize a population that very definitely has a great deal of inner resourcefulness and compassion. The strength of the survivors is as much a part of the data of multiple AIDS-related losses as are the emotional challenges of complicated bereavement.<sup>35</sup>

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<sup>33</sup> Ibid., 46-51.

<sup>34</sup> Shrader, 158.

<sup>35</sup> Ibid., 158-59.

This emphasis on the strength of survivors is well worth remembering in the context of the present research.

Like Shrader, Odets also points out the inadequacy of existing models of grieving for capturing the multiple nature of AIDS loss. He then goes on to specify some of the particular difficulties that gay men have faced in grieving AIDS losses. He notes, first, that multiple losses are more likely to be denied because mourners fear that, if they allow any grief, then they will be overwhelmed by their feelings.<sup>36</sup> Second, he describes the role that partial grieving or suppressed grieving of AIDS losses can play in creating discontinuity in emotional and interpersonal experience and a range of symptomatology. Finally, unresolved mourning may lead to a lack of psychological integration of the experience of loss.<sup>37</sup>

In summary, clinical and theoretical assessments of the effects of AIDS-related loss must attend carefully to the nature of this loss as multiple loss in attempting to describe and ameliorate it.

### **AIDS Loss as Traumatic Loss**

The recognition of AIDS loss as multiple loss leads quickly to the realization that AIDS loss may be understood as a form of trauma. Despite the value of viewing AIDS loss in this way, few treatments of AIDS loss, until quite recently, explored the parallels between AIDS loss and other forms of trauma. David Nord, in his review of multiple AIDS-related loss makes this point; he notes, "In books, scholarly articles and seminars

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<sup>36</sup> Odets, 90.

<sup>37</sup> Ibid., 92-93.

about AIDS, the topic of trauma is rarely mentioned in connection with surviving multiple AIDS-related loss.”<sup>38</sup> Nevertheless, he makes a strong case that viewing AIDS loss as a form of trauma provides helpful insights regarding the effects of loss and strategies for treatment. I have observed the same phenomenon and view recognition and exploration of this parallel *as the most promising avenue* for understanding and responding to AIDS-related multiple loss.

According to the DSM-IV, trauma may be defined as a confrontation with an event that involves actual or threatened death, serious injury, or a threat to the physical integrity of self or others.<sup>39</sup> Further, symptoms of trauma tend to cluster in three categories: persistent avoidance of stimuli associated with the trauma or generalized psychic numbing, recurrent distressful recollections associated with the traumatic event, and persistent symptoms of increased arousal.<sup>40</sup>

According to Nord, there are several important reasons for acknowledging the nature of AIDS-related multiple loss as traumatic loss. First, defining AIDS multiple loss as traumatic loss provides a context for understanding the experience of survivors. Second, it allows clinicians to draw on treatment options used for trauma as a resource in treating survivors of AIDS multiple loss. Third, viewing the experience as traumatic allows a framework for normalizing the abnormal experience.

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<sup>38</sup> Nord, 129.

<sup>39</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorder: DSM-IV*, 4<sup>th</sup> ed. (Washington, D.C.: American Psychiatric Association, 1994), 427.

<sup>40</sup> Nord, 130.

In his treatment of AIDS-related multiple loss as traumatic loss, Nord outlines the aspects of AIDS loss that qualify it as traumatic. They include:

- the quantity of loss sustained by survivors
- the disease process of AIDS, including the protracted nature of the illness, the heightening of uncertainty and anxiety caused by the episodic nature of the illness course, and the reactions of fear, horror and sadness associated with the physical symptoms of AIDS-related opportunistic infections.
- the cumulative toll of the many and varied losses associated with AIDS
- the ongoing traumatization associated with AIDS, i.e., the probability that the losses will continue, and
- the prematurity of death experienced by most persons with AIDS<sup>41</sup>

In his treatment of AIDS loss as traumatic loss, Nord also discusses the notion of community wide collective traumatization. His treatment of this topic is crucial to the present investigation, since it was my interest in the collective or communal aspects of bereavement that led to the decision to study the effects of AIDS loss on a particular congregation. Nord notes, first, that a traumatized community is less able to provide support to its individual members who experience multiple loss. This is one important way in which AIDS has differed from other disasters, such as plane crashes, in which losses tend to be diffused throughout a wider community. In isolated disasters, the remainder of the community is available to support survivors, whereas AIDS has tended to devastate *particular communities as a whole*. This makes it difficult for community members to support one another, since each person is struggling with his or her own burden of loss.

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<sup>41</sup> Ibid., 133-36.

Second, collective traumatization leads to a breakdown in the structure of communities. Within the gay community, entire “families of choice” have been struck down by AIDS. In Shrader’s research, he noted that many of the gay survivors he interviewed were “one of only two or three remaining members of Gay families or support systems that had included fifteen to twenty members.”<sup>42</sup> Further, since many gay and lesbian people live in “urban ghettos,” they have experienced the loss of many friends and acquaintances, including professionals they have patronized and owners and operators of the gay-owned and operated businesses they have frequented.

Finally, research on other forms of collective trauma supports the notion that traumatic impact is heightened when trauma affects an entire community. One of the most well-substantiated examples of the effects of trauma on a community is the research on the survivors of the Buffalo Creek disaster. This was a 1972 flood that destroyed many individuals and the community structure of Buffalo Creek, West Virginia. Perhaps the greatest loss in collective trauma is the loss of identity associated with the community’s existence. As Kai Erikson, a sociologist who studied that town, noted about the aftereffects in Buffalo Creek:

The collective trauma works its way slowly and even insidiously into the awareness of those who suffer from it . . . [it is] a form of shock – a gradual realization that the community no longer exists as a source of nurturance and that a part of the self had disappeared.<sup>43</sup>

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<sup>42</sup> Shrader, 89.

<sup>43</sup> Kai T. Erikson, “Loss of Communitarity at Buffalo Creek,” *American Journal of Psychiatry* 133, no. 3 ( March 1976): 302.

Identity may be understood as a collective phenomenon, in that most of us share important memories and beliefs with others in our lives. With the death of many loved ones, our own sense of our self is depleted.

Nord describes several characteristics that may predispose a given survivor to greater traumatization. He notes that there is generally a positive correlation between the number of deaths a given individual has sustained and the degree of traumatization he or she experiences. Other factors that increase the effect of trauma included the severity of stress an individual is facing, the possession of a prior history of trauma or other loss, pre-existing personality difficulties, defense mechanisms (such as a view of oneself as a chronic victim), coping styles, and, finally, concurrent health difficulties, including an HIV-positive diagnosis. He also notes the importance of recognizing secondary traumatic stress, a form of stress that may affect professionals, volunteers, and others who provide care for persons with AIDS. Burnout among such individuals is a clue to the presence of traumatic stress.

Nord provides a very helpful characterization of certain psychological effects of AIDS-related multiple loss that stem from the traumatic nature of the loss. These include the damaging effects that AIDS loss has on world view. As we have already noted, AIDS loss may have a profound effect on an individual's identity, and it may also shatter certain primary assumptions people hold about the world, including the beliefs that the world is comprehensible, orderly and sensible and that "I am invulnerable." AIDS loss also leaves a death imprint or permanent psychological mark in those who

have witnessed many AIDS deaths.<sup>44</sup> AIDS may also create a state akin to learned helplessness in survivors. They may feel powerless to prevent the death of loved ones, to eliminate the pain of persons with AIDS, to control the extent of their future losses or to escape a world saturated with AIDS. This may result in depression, diffuse anger, and motivational disturbances in survivors. In addition, survivors may struggle with alternating experiences of psychic numbing and intrusive thoughts.

Nord concludes his review by emphasizing that there is, at present, no psychiatric diagnostic category that adequately reflects the nature of AIDS loss as multiple loss. For example, the category "post-traumatic stress disorder" assumes that the trauma is in the past. He suggests the addition of a diagnostic category entitled *multiple AIDS-related loss syndrome* to allow for more accurate assessment and treatment of AIDS survivors. Given the continuing prevalence of AIDS loss around the world, this suggestion seems both timely and helpful.

### **Towards an Integrative Model of Treatment**

Following their extensive and helpful review of the literature on AIDS bereavement, Peter Goldblum and Sarah Erickson propose an integrative model for assessing and treating AIDS bereavement. The presentation of this model can serve as a summary for this discussion of psychological aspects of AIDS loss. Goldblum and Erickson note that a central tenet of their integrative model is that bereavement distress is not a single entity. Effective treatment requires precise assessment so that clinicians can identify and address the particular needs of individual mourners.

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<sup>44</sup> This terminology is based on the work of Robert Jay Lifton which will be extensively reviewed in Chaps. 6 and 9.

The first step in assessment is to determine whether the mourner's grief is complicated or uncomplicated. Complicated grief is characterized by:

An atypical intensity (overly numbed or overly intrusive) or duration (absent or chronic) of grief symptoms (shock, yearning, searching, disorganization, despair) which leads to an unacceptable duration of functional impairment in critical areas of work and relations.<sup>45</sup>

Different theorists emphasize different aspects of this definition in their approach to identifying complicated bereavement. However, in addressing assessment, Goldblum and Erickson do note that in up to twenty percent of mourners, intense symptoms of grief are absent. Therefore, both the presence and absence of symptoms must be carefully evaluated in light of the cultural context and the mourner's adaptive functioning to determine if grief is complicated.

The second step in assessment is to determine if the grief reaction is accompanied by a mental disorder. The term co-morbidity applies when grief co-exists with other psychiatric complaints. The most common accompaniments to bereavement are depression and anxiety disorders. In fact, they note that full depressive episodes are not unusual in the first year following the death of a spouse. These depressive symptoms, even when seen early in loss, may be distinguished from bereavement, *per se*. Anxiety disorders accompanying AIDS bereavement may include panic disorder, generalized anxiety disorder and post-traumatic stress disorder.

The third step in assessment is to probe for the presence of risk factors for AIDS bereavement distress. Goldblum and Erickson note that these are of two kinds. The first

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<sup>45</sup> Goldblum and Erickson, 32.



category of risk factors are bereavement burdens. These consist of potential stressors or demands placed on mourners. The second category, personal impediments to coping, reflect characteristics of mourners or ongoing problems that may interfere with their ability to appraise and cope with bereavement distress. Goldblum and Erickson list six bereavement burdens. They include:

- being HIV infected
- being a caregiver, spouse, primary partner or parent of the deceased
- perceiving interpersonal conflict or a lack of social support for the survivor
- experiencing an accumulation of stressors (e.g., unemployment, financial difficulties)
- being young, and
- experiencing difficulty resolving a relationship with the deceased

In assessing the impact of these burdens, therapists must attend to the number of burdens present as well as the severity of each.

After assessing for the presence of bereavement burdens, therapists must then determine whether there are impediments to coping. These impediments include:

- the use of ineffective and avoidant coping strategies, including substance abuse, overeating, or sex.
- the use of ruminative coping, or excessive attention to one's personality and internal state. This is associated with a higher incidence of depression.
- the presence of guilt and lowered self esteem. This may be associated with a negative evaluation of one's caregiving efforts.
- reliance on negative thinking.
- the presence of pre-existing substance abuse or dependency. This can block, delay or prolong mourning and may increase the risk of suicide.

Once careful assessment has been made, clinicians may then draw on a variety of treatment resources. These may include resources for education and support, including bereavement support groups and bereavement risk reduction counseling; psychiatric and medical interventions, particularly for co-morbidity; and psychotherapy for complicated

grief. The latter may be problem-oriented and focus on behavior change or psychodynamic and focus on resolving underlying blockages in the mourning process.

When providing therapy for AIDS mourners, the authors identify several goals. These include modulating the intensity and duration of grief symptoms, reducing functional impairment in work and relationships and reducing symptoms of clinical disorders. To this end, they identify four therapeutic tasks. The therapist must:

- establish rapport, validate the loss and listen carefully to the client's story as a way of establishing shared goals
- develop an integrative and dynamic understanding, completing the phases of assessment described above
- work through psychodynamic blocks, facilitate behavioral change, and
- reinforce positive changes and terminate the therapy.

Goldblum and Erickson's model provides a comprehensive and helpful tool for evaluating the varied and complex aspects of AIDS loss. It provides professionals with a framework both for interpreting and responding to AIDS mourners and draws effectively on current research as well as the authors' extensive clinical experience.

In summary, therefore, our discussion of the psychological aspects of AIDS loss has focused on the contextual variables that shape the experience, the nature of AIDS loss as multiple and as traumatic, and the need for an integrative model of assessment and treatment.

### **The Problem of AIDS-Related Loss: Its Human Face**

Our descriptive analysis of the problem of AIDS related loss has thus far focused on the magnitude of AIDS loss, social, political and religious aspects related to its management and the psychological toll it takes on survivors. Consideration of each of these aspects of the problem of AIDS loss has raised many questions: How can we

understand a problem of this magnitude? Why are some populations at great risk, whereas others seem relatively invulnerable? How can we ease the pain of those who suffer at home and abroad? Are we in any way responsible for the great amount of loss and pain AIDS has wrought? As we allow our hearts to be touched by the magnitude of loss and the suffering associated with AIDS, we find ourselves confronting existential questions about life, loss and love.

To reflect further on these vexing questions, we shall now turn to a preliminary consideration of the theological and spiritual aspects of AIDS loss. This discussion will provide some important guideposts for the constructive work that will follow in Parts 2 and 3 of this study.

## CHAPTER 4

### “NO LONGER DO I CALL YOU SERVANTS”: TOWARD A THEOLOGY AND SPIRITUALITY OF AIDS LOSS

Surely the task for the Church is to cease laboring so much over the construction of elaborate theodicies and clever moral responses for AIDS, to cease all of that and simply to cherish who we are as persons: lonely, hurting, frightened, loving, healing, encouraging human beings who need each other desperately . . . Will we not begin to see that sin is truly alienation, the rejection and loneliness of others? Will we not then begin to see that wickedness is in the prejudice which stigmatizes fellow human beings, promoting misunderstanding, forcing us apart and not together? Will we then not begin to abhor and end the exile which some have had to endure, pent-up within themselves and guilty, facing an illness alone and unsupported, their fears not listened to and their anger unheard? Will we not begin to affirm the supportive friendships of gay people and drug users alongside the accepted ties of family and marriage?<sup>1</sup>

Nowhere . . . have I found the resurrection meaning more fully embodied than in the community affected by AIDS that I am privileged to be a part of. This community is owning the release of the body as a carrier of love, and it is owning the power of unconditional love, in ways that, I daresay, constitute something new in history. If I am right, the power of the resurrection is breaking through in this community, and it is breaking through for all of us. The experience of this community *will* make a difference, and the difference will be experienced by anyone who takes the time to savor the reality and become a part of it.<sup>2</sup>

The purpose of this chapter is to offer some preliminary reflections on theology and spirituality in light of AIDS loss. I shall begin by laying groundwork for the consideration of these distinct forms of human experience. Since questions of theology

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<sup>1</sup> Mark Pryce, “New Showings: God Revealed in Friendship,” in *Embracing the Chaos: Theological Responses to AIDS*, ed. James Woodward (London: SPCK, 1990), 55.

<sup>2</sup> Robert Doran, “AIDS Ministry as a Praxis of Hope,” in *Jesus Crucified and Risen: Essays in Spirituality and Theology in Honor of Dom Sebastian Moore*, ed. William P. Loewe and Vernon J. Gregson. (Collegeville, Minn: Liturgical Press, 1998), 180.

and spirituality will be central to discussions in the following chapters the treatment in this chapter will be brief.

My interest in exploring issues of theology and spirituality related to AIDS grew directly out of my pastoral experience with persons living with HIV, AIDS and AIDS loss. In the period of my most intense pastoral work, I began the deliberate process of theological reflection on AIDS because I was attempting to find a way to maintain my own faith and to experience hope in the face of the challenges AIDS represented. I have already described how the destructiveness of AIDS on persons and their relationships, the painful suffering I witnessed in those living with it, and the premature deaths of many persons with AIDS struck at my foundational beliefs about God, creation, eschatology and ecclesiology. Simply put, my beliefs were inadequate to the pastoral challenges I faced, and they needed reworking. Since that time I have come to understand that because AIDS impinges on aspects of Christian theology and spirituality that have caused the Church perennial problems, particularly its treatments of sin and sexuality, exploration of the theological and spiritual aspects of AIDS loss is a most worthwhile endeavor.

### **Definition of Terms**

Considerable conversation in the past ten years has been devoted to the relationship between theology and spirituality. This discussion has been prompted, in part, by the emergence of spirituality as a field of interdisciplinary study that is related to theology but can be distinguished from it. In his study of the relationship between theology and spirituality, Philip Sheldrake identifies three ways in which this relationship

has been understood.<sup>3</sup> The first position, identified with Sandra Schneiders, is that spirituality and theology “are close partners that function in mutuality but respect each other’s autonomy.”<sup>4</sup> Schneiders does not believe that spirituality can be subordinated to theology, because spirituality is ultimately interdisciplinary in nature and cannot be considered a strictly Christian phenomenon. Further, in her view, even Christian spirituality is not limited to the outworking of Christian doctrines.

The second position describing the relationship between spirituality and theology is that of Bernard McGinn, a scholar of spirituality, who believes that spirituality is primary in its partnership with theology. McGinn believes that religious experience is properly the concern of a healthy theology and that spirituality is most effectively taught within a combination of theological disciplines.

The third position is that espoused by Sheldrake himself. He believes that there is a central relationship between theology and spirituality, but that spirituality should not be seen as a distinct discipline. He argues that “theology must come to realize more effectively its own, essential inner core.”<sup>5</sup> In other words, “spirituality and theology need to be re-integrated.”<sup>6</sup> That being said, however, Sheldrake admits that while spirituality exists in a core relationship to theology, spirituality also points beyond the constraints of a purely theological discipline and method.

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<sup>3</sup> Philip Sheldrake, *Spirituality and Theology: Christian Living and the Doctrine of God* (Maryknoll, NY: Orbis, 1998).

<sup>4</sup> Ibid., 84.

<sup>5</sup> Ibid., 86.

<sup>6</sup> Ibid., 87.

Schneiders' understanding of the relationship between theology and spirituality works best within the context of AIDS and AIDS loss. This is because her definition of spirituality rests upon an understanding of the spiritual life as "an existential project . . . the project of self-integration through self-transcendence within and toward the horizon of ultimacy."<sup>7</sup> Because many people living with AIDS loss are not Christian or are post-Christian, adopting a broader definition of spirituality provides the most useful tool for discussing the quality of life as affected by AIDS loss. Nevertheless, Schneiders does specify that in the case of Christians, the horizon of ultimacy is "God revealed in Jesus Christ who is present as Spirit in and through the community of faith called the Church."<sup>8</sup> Thus, her definition describes a process, self-integration through self-transcendence that can be understood as common to Christians and non-Christians alike. What differs is the content: the horizon of ultimacy for Christians is the revelation of God in Christ.

While Schneiders rightfully notes that, because the interaction of the divine and human Spirit is not understood solely in terms of the submission of the human to the divine, "Christian spirituality cannot be reduced without remainder to either the theologically Christian or the exclusively religious."<sup>9</sup> She argues, for example, that both feminism and psychotherapy are integral to Christian spirituality for many people, yet neither of these phenomena is essentially religious. Her broad and tolerant perspective

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<sup>7</sup> Sandra Schneiders, "A Hermeneutical Approach to the Study of Christian Spirituality," *Christian Spirituality Bulletin* 2, no. 1 (spring 1994): 10.

<sup>8</sup> Ibid., 10. In this work, Schneiders does not note explicitly that it is possible to have a spirituality that is theistic but not religious. Twelve step spiritualities provide an example of this phenomenon. In her words, twelve step spiritualities could perhaps be thought of as theological and including "more than specifically Christian content." Ibid., 10.

<sup>9</sup> Ibid.

opens the door to new approaches to spirituality, such as those called for by Richard Hardy. Hardy, a Roman Catholic theologian and scholar of spirituality, has worked extensively in the gay community and among persons with AIDS and AIDS survivors. He has called for scholars of spirituality to move beyond simply presenting those things that are considered “truly spiritual” and to “break out of the denominational dogmatic doldrums which most often keep us from seeing the creative work of the Spirit in our time.”<sup>10</sup> Since the communities affected by AIDS are frequently marginalized by churches, the adoption of this broader approach to spirituality advocated both by Hardy and Schneiders offers the greatest promise for describing the varied activities of Spirit within them. Further, there is value to adopting a definition that allows us to understand a common *process* of spirituality despite divergent content.

Through my exposure to the literature on AIDS bereavement, I have come to understand the distinction between the theology and spirituality of bereavement in a particular way. In my view, theological questions refer primarily to the *understanding* of the experience of the loss in light of one’s relationship to the ultimate. In contrast, questions of spirituality refer to attempts to integrate these understandings arising from the experience of loss into the humanity of the bereaved. Theological understandings lay the groundwork for the spiritual response, and the experience of loss shapes these understandings, in turn.<sup>11</sup> It should be emphasized, however, that the spiritual response

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<sup>10</sup> Richard Hardy, “Coming Out of Our Spiritual Closets,” *Christian Spirituality Bulletin* 7, no. 2 (fall/winter 1999): 18.

<sup>11</sup> Adoption of this distinction is not meant to minimize the implications of either theology or spirituality for praxis.



includes much more than a cognitive integration, as spirituality is wholistic and involves the entire being of the bereaved.

Some common theological questions raised by the experience of AIDS loss include the following: What kind of God allows this experience? Is God trustworthy? Am I being punished? Where is God in this experience? Is God responsible for the loss of my loved ones? Is the world trustworthy? How/can I maintain hope? Is my loved one alive somewhere? Will I be reunited with my loved one?

Questions of spirituality, in contrast, include direct concerns about the implications of the loss for day to day life. They include such questions as: Can/will my life have meaning and purpose despite these losses? How/can I heal? How am I to live now? How/can I integrate this experience with other aspects of my life and understanding? How/can this experience contribute to greater wholeness? Greater authenticity? Greater faith?

As this cursory review has suggested, it is clearly difficult to separate the domains of spirituality and theology in practice, since developments in one area have implications for the other. Nevertheless, we shall adopt this thumbnail distinction between theology and spirituality in the context of AIDS loss for the purpose of the present discussion.

### **The Theological Aspects of AIDS and AIDS Loss**

As Leslie Houlden notes in his reflection on AIDS in a biblical perspective, AIDS raises no new theological problems.<sup>12</sup> The theological questions arising in life with HIV and AIDS have arisen in other situations of suffering and traumatic loss. The fact that

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<sup>12</sup> Leslie Houlden, "In a Biblical Perspective," in *Embracing the Chaos*, 103.

these questions are not new, however, does not detract from their urgency or from the need for us to re-examine the foundations of faith in this new context. The depth of suffering caused by AIDS demands this re-examination, and it is incumbent upon those of us who minister to explore the basis for the hope we profess.

This reflection on the theology and spirituality of AIDS loss draws heavily on my own experience and understanding. It shall attend to five themes central to the consideration of AIDS loss: the nature of God and creation, sin, the basis for hope in suffering and loss, community, and remembrance. These particular themes are developed for three reasons: first, they appear extensively in the AIDS literature; second, they are central to the work of Julian of Norwich and thus offer promise for understanding and responding to multiple loss; third, they have emerged as critically important themes in my pastoral work at San Francisco General Hospital and in the All Saints interviews.

#### The Nature of God and Creation

The challenges posed by AIDS and AIDS loss lead inevitably to a consideration of the nature of God. *What kind* of God allows such suffering? we ask, amid pain and loss. Through the long vigil required by the disease and in the sleepless nights of grief, we also ask, *Where* is God? Have we been forsaken?

Reflection on the nature of HIV disease and AIDS loss suggests that these experiences draw us into the heart of the Trinity. Certainly, there are times when even this conceptualization of God seems to fail, for its very mystery defies attempts to fathom easily the nature of the divine. Nevertheless, the challenges posed by AIDS and resolutions to them require a God of love who engenders community, embraces diversity and is oriented toward a hopeful future.

A very effective articulation of the Trinitarian dynamics applied to AIDS comes from Peter Baelz.<sup>13</sup> In his analysis of the Trinity, Baelz emphasizes the economy of the Trinity, or the work of creation, redemption and fulfillment. With regard to creation, Baelz describes the ongoingness, freedom and patience of God's creative work. He describes the way in which God authorizes creation, giving it the authority of love to be itself. Thus, God makes time and space for creatures who are dependent on God but who have a reality and independence of their own. In creating, God draws on a pattern that includes trial and error, a combination of order and disorder, randomness and necessity. Because of this,

There is no guarantee that things will not 'go wrong.' In fact, there is every indication that things have gone wrong and will continue to go wrong.<sup>14</sup>

The riskiness of creation is manifested, among other places, in natural disasters and in disease. After reviewing current theory in biological and physical science, Baelz reports that creation involves an interdependence of randomness and order. Yet, within this flux of energy and life, three underlying tendencies can be discerned: a tendency of smaller units to combine, a tendency towards greater independence and a tendency towards a deeper capacity for suffering.<sup>15</sup> The first two, taken together, he interprets as a move toward interdependence, while the third implies an openness and vulnerability that is at the heart of the creative process. Understanding these tendencies leads naturally to

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<sup>13</sup> Peter Baelz, "What Sort of World? What Sort of God?" in *Embracing the Chaos*, see esp. pages 114-15. The reader will note that Baelz' essay, written over 10 years ago, does not use inclusive language for the divine. I believe that understanding God in a more inclusive way is not at all inconsistent with the author's emphases.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid., 113.

consideration, first, of ourselves as creatures and second, to the nature of Christ and the process of redemption.

With regard to ourselves as creatures, two implications flow from the notion of an ongoing and risky creation. The first derives from the approach of process theology: if the work of creation is ongoing, then there is room for us to participate as co-creators with God. This understanding provides a framework that both values and encourages human efforts to eradicate HIV disease. The second implication regards human nature: since we are creatures, we find ourselves to be no more nor less exempt from the ongoingness of creation than any other aspect of the created order. Understanding this fact explains, in part, our susceptibility to the ravages of disease, since these are part and parcel of the present experience of creation. Thus, the human experience is one of limitation, but not one of powerlessness. While we do become ill, we are able to engage our creative powers in attempts to heal.

Here, however, is where understanding the redemptive process is crucial. Jesus Christ, the second person of the Trinity, attests to God's love for the created order, including human beings. The incarnation is God's answer to the questions, What kind of God? and where is God? In Jesus, we encounter God as unconditional love and compassion in our very midst. The incarnation reveals a God who gives us Godself.

According to this understanding, God is present with us amid the ravages of AIDS and in the pain of loss. God is present in the love and care we extend to one another as particular incarnations of God's love. The Trinitarian understanding of God, therefore, offers insight into our nature and call, at the same time as it enhances our understanding of God.

The third aspect of the Trinity's work is fulfillment. As Baelz notes:

What [God] has to share with his creatures is nothing less than the fullness of his own life. In and through the work of creation and redemption he struggles to elicit from his creatures, singly and together, their deepest potentialities so that they may enter into the glorious liberty of the children of God.<sup>16</sup>

Describing God's work as fulfilling implies that God will not abandon either the creative process or God's creatures until the work of creation is brought to completion.

On the one hand, the understanding of God that Baelz offers is not always an easy one to embrace, since it implies that the suffering resulting from the ongoingness of creation is an inevitable part of human existence. On the other hand, the notion of God's presence and love incarnated amid this suffering is a potent reason for hope. The understanding of the presence of God's love as hope is embraced within the concept of the resurrection.

### Sin

Attending to the concept of sin is absolutely critical to any theological discussion of AIDS and AIDS loss since, as we have noted, the Christian right interpreted AIDS as God's punishment for homosexuality.<sup>17</sup>

As the history of the churches' response to AIDS makes clear, life with HIV disease and AIDS has pointed out deficiencies in the Church's approach to human sexuality. These result in part from traditional conceptualizations of sin. Kenneth Leech describes the way in which two historic forces have led to an equation of sex with sin.

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<sup>16</sup> Ibid., 115.

<sup>17</sup> Andriote, *Victory Deferred*, 69 contains the statements of such spokespersons as Jerry Falwell and Pat Buchanan.

First, the “persistence of the gnostic Manichean tradition of the inherited sinfulness of the flesh” has left its mark on Christianity, even as it has been repudiated through the work of Patristic writers such as Clement of Alexandria, Origen and Augustine.<sup>18</sup> The “dread of women” that has characterized the Christian church has also influenced the understanding of sin. For centuries, women were viewed as representatives of passion, “the irrational instinctive realm of carnality,” and as a source of temptation to men.<sup>19</sup> As a result, Leech concludes that “sex and the spirit are not seen to belong together [and ][s]ex only figures in the pastoral arena in the form of sin.”<sup>20</sup>

The equation of sin with sex has complicated the church’s treatment of same sex love. As William Lindsey notes in his discussion of the AIDS crisis and healing, the Christian churches have tended toward either one of two positions with regard to gay and lesbian persons. Either they have maintained that a homosexual orientation is intrinsically disordered or, if granting the same sex orientation moral neutrality, they have held that genital sexual activity on the basis of that orientation is objectively sinful. According to Lindsey, a troubling implication flows from these positions:

For many gay persons with AIDS these theological convictions assure that the church’s healing concern appears ultimately to be directed to *someone other* than the patients themselves. By divorcing the sexuality of gay people from their humanity, or by treating sexual orientation or activity as accidental to that humanity, the church gives the impression of ministering not to actual persons who are suffering *qua* persons, but to bodies separated from psyches.<sup>21</sup>

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<sup>18</sup> Kenneth Leech, “‘The Carnality of Grace’: Sexuality, Spirituality and Pastoral Ministry,” in *Embracing the Chaos*, 59.

<sup>19</sup> *Ibid.*, 60.

<sup>20</sup> *Ibid.*

<sup>21</sup> William D. Lindsey, “The AIDS Crisis and the Church: A Time to Heal,” in *Christian Perspectives on Sexuality and Gender*, ed. Elizabeth Stuart and Adrian Thatcher (Grand Rapids: W. B. Eerdmans, 1996), 349 (original emphasis).

Thus, the traditional treatment of same sex love results in a form of dualism that undermines the humanity of gay and lesbian people. It is a short step from this position to the condemnation of gays and lesbians that was promulgated by some Christians early in the epidemic in pronouncing AIDS as a form of God's punishment on gays.

Stigmatization of gays by the church has resulted in their stigmatization by society at large. This stigmatization constitutes an unacceptable form of violence that continues to be perpetrated by churches in their refusal to acknowledge the blessing inherent in same sex love and to allow gays and lesbians full participation in the church's sacramental life.

The way out of this quandary lies, in part, in re-conceiving the notion of sin. In a very helpful essay, Mary Elizabeth Mullino Moore critiques the limited view of human goodness that arises when goodness is defined in contrast to traditional understandings of sin. She then illustrates the way in which the sexist social realities facing women in the church can be reframed through the adoption of a new view of human goodness. As she notes, the implications of this reconsideration of sin and goodness apply to gay and lesbian people as well as to others who experience stigmatization. Her view is that the traditional identification of sin with sexuality, power and chaos has tended to reinforce oppression. She argues for re-conceiving sin in three specific ways: as *refusing to receive the gifts and blessings we have been given*, as *denying or thwarting chaos and creativity* and as *a way of being in the world that destroys or denies life*. Sin, then, can be

understood as “*alienation from God and the world* – a moving *against* relationship rather than a participation in a relationship that is life-sustaining.”<sup>22</sup>

In a similar way, Lindsey argues for a paradigm shift in Christian social ethics, espousing a turn toward the social subject. In his view, the AIDS crisis reveals that sexual ethics demand social ethics. Adopting a social ethic frees the church from consideration of nature, allowing instead an examination of how social structures influence the lives of gays and lesbians. As he notes, this examination highlights how the social discourse discriminating against gays and lesbians lies in issues of difference and in misogyny, rather than in anything intrinsic to “gayness” itself. Recognition of this pattern paves the way for the adoption of a liberationist stance in the approach to gay and lesbian life.

The value of these proposals is that they allow the recovery in Christian theology of the full humanity of gay and lesbian people. Further, they help to conceptualize the damaging effects of the churches’ continuing inability to embrace fully the gifts and blessings embodied in the being and love of gays and lesbians. Here, the church’s traditional condemnation and exclusion of gays may be seen as the *true* repudiation of goodness and as a denial of life. Accepting this view highlights the need for the church to repent for the way in which her stigmatization of gays increased both the amount of AIDS loss and the suffering of survivors. First, the church’s stigmatization of gays contributed to society’s tendency early in the epidemic to deny the importance of gay deaths. Second, the increased suffering of mourners resulted from their choice to isolate themselves with

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<sup>22</sup> Mary Elizabeth Mullino Moore, “Feminist Practical Theology and the Future of the Church,” in *Practical Theology: International Perspectives*, ed. Friedrich Schweitzer and Johannes A. van der Ven (Frankfurt: Peter Lang, 1999), 199-200 (original emphasis).



their loss rather than to reveal publicly that their loved ones had died of AIDS and to risk suffering secondary stigmatization.

In summary, therefore, traditional notions of sin have increased the amount of suffering associated with AIDS and AIDS loss. Revision of the Christian understanding of sin is crucial to the formulation of an adequate theology of AIDS and to a renewed pastoral praxis.

### Hope

Attending to the basis for hope is crucial in the AIDS pandemic when the massive amount of death associated with it seems, at times, to call the very continuity of life into question. Further, the enormous amount of human potential lost as a result of the epidemic undermines confidence in the goodness of God and of life.

The basis for hope in the Christian faith is the resurrection event. Resurrection speaks of the possibility of life amid death and reminds us that the power of love and creativity exceed the power of death and destruction.

As Robert Doran notes, there are two aspects of hope related to resurrection. The first is hope for the conquering of death, while the second is hope for our lives together in communal history.<sup>23</sup> Hope for the conquering of death rests in the belief that “in the resurrection of Jesus Christ death is overcome for us all.”<sup>24</sup> In developing this first aspect of hope, Doran continues, “Death is a passage to a new and glorious life in which there is no more pain, no more crying, no more grief, for these former things have passed

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<sup>23</sup> Doran, “AIDS Ministry as a Praxis of Hope,” 178.

<sup>24</sup> Ibid.

away.”<sup>25</sup> Scripture testifies to these realities. On the one hand, many people long for this release, and the language of our liturgy nurtures this hope. On the other hand, some people who may be agnostic about this ultimate hope find resurrection hope in the experience of AIDS in *this* world. It may be found in the presence of love amid pain and in the promise of medical advances to control and ultimately cure AIDS. Doran, however, testifies to a second aspect of hope: the hope that the community, powerfully united to meet the challenge of AIDS, will make a positive difference in the world. Hope is trust that the community

will make a difference in history, will change the way that people live, that it will not simply be forgotten when AIDS is over, that it will be remembered, that the love AIDS called forth will be forever celebrated, that the community affected by AIDS will be changed for the better by the indelible memory of the way it rose to the occasion in love and service, and that the rest of the world will adopt a new attitude toward this community.<sup>26</sup>

Doran is speaking specifically of the gay and lesbian community. However, this vision of resurrection life expressed in *justice* may be applied to others affected by AIDS. That is, resurrection life can be expressed through a transformation of oppressive attitudes towards gays and lesbians, the young, persons of color, sex workers, IV drug users, and hemophiliacs. The view of resurrection life as justice celebrates the triumph of life and love wherever they are found in the midst of the epidemic. The hope of the resurrection, conceived as a hope for justice, suggests that, while we cannot know with certainty what lies beyond death, we can ensure that no one must face it alone.

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<sup>25</sup> Ibid., 178-89.

<sup>26</sup> Ibid., 179.

As Doran indicates and I have experienced, the heart of resurrection life is love. Amid life with AIDS, many experience the transforming power of love in the midst of the pain and moments when the Spirit of God breaks through to change forever understandings of life and death. The experience of God's Spirit may be mediated through other people or felt more directly. However it is perceived, experiencing unconditional love has the power to remove the fear of death and to enable one to live with joy and acceptance of life, death and one's fellow travelers. Doran notes how the experience of being unconditionally loved *is* sanctifying grace.<sup>27</sup> He states further that he learned this from his friends who were living with AIDS in Toronto; "from the lovers who show the fidelity and tenderness that make their experience holy."<sup>28</sup> The experience of love is not unique to life with AIDS, but it is also no stranger to life with AIDS, and when it is received as gift and blessing, it is a potent source of hope.

In addition to the aspects of hope Doran describes, hope in AIDS may also be found in renewed appreciation for the day to day life events that not infrequently accompany illness. When this appreciation is shared, it is a source of new life that can enrich relationships. The friends of Lloyd, a young man who died of AIDS, described how his appreciation of life amid illness enriched their lives. Although Lloyd's life was restricted by illness and his dependency increased, he did have more time for reflection and awareness. As a consequence, he "saw more the joys of simple everyday things, human company and real values so easily taken for granted otherwise."<sup>29</sup> As his illness

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<sup>27</sup> Ibid., 192-93.

<sup>28</sup> Ibid., 193.

<sup>29</sup> "Lloyd," in *Embracing the Chaos*, 33-34.

progressed, Lloyd became more dependent on his partner, yet others became more dependent on him.

Lloyd's love for them was vivid. . . . In the months before his passing, people felt their bond with Lloyd growing, and saw his sensitivity and insight into their own lives; from the richness of his unfolding experience he could lend his own sense of proportion to others' cares and concerns. . . .<sup>30</sup>

This description suggests that the experience of resurrection life can be relational. As those living with AIDS are transformed, their loved ones are renewed.

It is important to remember, as Stephen Pattison reminds us, that the experience of new life is not always tidy. He notes, "New life can be as disruptive and unwelcome as sudden death."<sup>31</sup> Further, new life is often experienced at the margins of church and society where life and death mingle. These realities are a constant challenge to the church, despite the fact that the paschal mystery is at the core of its identity. The experience of life with AIDS has exemplified the tensions between stability and change and between institutional order and pastoral ferment that are part of the dynamism of the resurrection event. The hope for Church and world is that the experience of love at the core of resurrection will allow movements toward justice and inclusion to emerge as fruits of life with AIDS.

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<sup>30</sup> Ibid.

## Community

Developing a theology of community is important to understanding the theology of AIDS for three reasons. First, AIDS is experienced in communities. Second, the support of communities as a whole makes life with AIDS and AIDS loss possible, since the burdens of AIDS and AIDS loss are simply too great to be borne by isolated individuals. Third, as noted above, the community provides the context in which new life is experienced. Since resurrection is relational, understanding the theological nature of community is essential.

In his treatment of the effects of HIV disease, Andrew Henderson reminds us that the experience of new life in AIDS has frequently been mediated through communities. Whether these are larger communities, such as congregations, or smaller ones, such as support groups, the experience of healing mediated through the community reminds us not to “over-individualize or to privatize conversion, belief or spiritual practice.”<sup>32</sup> As he notes, the church’s view of salvation is a communal one, expressed in the metaphor of the reign of God. While there may be tensions between older, more established church communities and the “communities of spirit” that support those living with AIDS and HIV, life with AIDS provides us with another opportunity to “make a living reality of the knowledge we already have.”<sup>33</sup> This knowledge is that

we are most fully ourselves, the people God made us to be, when we are members one of another; not dependent or independent but spiritually

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13. <sup>31</sup> Stephen Pattison, “To the Churches with Love from the Lighthouse,” in *Embracing the Chaos*,

<sup>32</sup> Andrew Henderson, “Members One of Another,” in *Embracing the Chaos*, 37

<sup>33</sup> Ibid.

interdependent through a shared commitment. . . . [T]he way to transform AIDS must be to make it the occasion for our salvation, so that we begin to live in real interdependence with each other, and are ready to explore the consequences of what that might mean.<sup>34</sup>

The enhanced experience of interdependence may be one of the most potent aspects of life in communities devastated by HIV and AIDS. The ravages of illness and the demands of caregiving have caused many communities afflicted with AIDS to discover the strength that comes from sharing the burdens of caregiving, as members learn to spell one another in responding to those in need. When facing the demands of cumulative grief, it is imperative that members of grieving communities learn to set clear boundaries and acknowledge their needs for support and respite. To do so without undue guilt in the face of traumatic loss requires genuine grace. Learning to avail oneself of the power of community in such circumstances, however, may provide some with the most potent experiences of interdependence and renewing love that they have known.

### Remembrance

Attending to the theme of remembrance is critical in developing a theology of AIDS. Remembering the beloved dead makes the doctrine of the communion of saints concrete. This doctrine testifies to the power of memory in transforming the suffering of AIDS and AIDS loss and in changing the world.

One of the most arresting symbols of hope birthed in the AIDS crisis is the AIDS quilt. This quilt testifies to what Elizabeth A. Johnson describes as the power of “subversive memory.”<sup>35</sup> Subversive memory is memory that “dares to connect with the

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<sup>34</sup> Ibid., 44.

<sup>35</sup> Elizabeth Johnson. *Friends of God and Prophets: A Feminist Theological Reading of the Communion of Saints* (New York: Continuum, 1998), 164-70.

pain, the beauty, the defeat, the victory of love and freedom, and the unfinished agenda of those who went before.”<sup>36</sup> It challenges oppression and energizes those who would birth justice amid present pain. The quilt has been used as a potent tool for change -- it serves as a sacramental reminder of the many individuals whose deaths were hastened through society’s denial of AIDS, and it testifies in a powerful way to the sanctity of their lives. Viewing the quilt and sharing the stories of loved ones who have died from AIDS awaken both hope and resistance. These practices infuse the traditional notion of the communion of saints with new meaning, meaning which may support efforts to bring about justice. In this way,

the communion of saints becomes a cloud of witnesses, surrounding those who cry for justice with encouragement and blessing, lending the support of their own witness for personal and social transformation.<sup>37</sup>

Indeed, remembering loved ones who have died from AIDS provides survivors with energy and purpose to address the wrongs that led to their death. The subversive memories of their deaths, especially when interpreted in light of the paschal mystery, gift the community of faith with an even deeper appreciation of the caring interdependence that characterizes God’s reign. Further, these subversive memories fuel the desire to realize the vision of inclusive love central to the expression of God’s reign.

In this discussion, therefore, we have reviewed ways in which life with HIV disease challenges us to reconsider and to reconstruct concepts central to the Christian faith. Reconstructions have been offered for creation, sin, resurrection, community and

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<sup>36</sup> Ibid., 165.

<sup>37</sup> Ibid., 180.

remembrance. In attempting to account for hope (1 Peter 3:15), new ways to express the human longing for God's love and healing emerge amid suffering and loss. Reflection on life with AIDS leads to a fuller understanding of goodness, a deeper appreciation of the energizing and sacred power of embodied love and of the varied ways that this love is expressed in communities. At the same time, the memories of loved ones provide a compelling incentive to seek the justice and inclusive love that too often were denied them in their life with AIDS. In all these ways, the experience of loss testifies to the presence of love that, however dangerous, provides a potent reminder of God who offers wholeness.

### **Spirituality, AIDS and AIDS Loss**

Even a cursory review of the literature on the spirituality of AIDS and AIDS loss indicates that definitions of spirituality vary widely. Particularly within the context of AIDS, writers on spirituality take care to distinguish between a humanist and religious spirituality. A humanist notion of spirituality, such as the one offered by Sandra Schneiders above, grounds its understanding of spirituality in the character of human nature rather than in a relationship to a particular religious tradition or to the divine.<sup>38</sup> This distinction, while not restricted to the discussion of AIDS spirituality, is particularly important to it because many people living with AIDS and surviving AIDS loss have been rejected by communities of faith. Gay and lesbian people, in particular, have had the experience of rejection from the church. Therefore, in developing their spirituality, they draw widely on the range of human experience.

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<sup>38</sup> Daniel A. Helminiak, "Non-Religious Lesbians and Gays Facing AIDS: A Fully Psychological Approach to Spirituality," *Pastoral Psychology* 43, no. 5 (1995): 301-18. See Schneiders' definition on page 96 above.



A brief overview of the definitions of spirituality that appear in discussions of spirituality and AIDS will provide us with the framework for this review. In the literature on AIDS, Daniel Helminiak has defined spirituality as “a built-in self-transcendence that pushes toward a broader and deeper grasp of life.”<sup>39</sup> In providing another humanist definition, Richard Hardy describes spirituality as “the whole life of a person lived in relationship with a transcendent value which calls out to us to abandon selfishness and self-centredness.”<sup>40</sup> Each of these definitions stresses the notion of self-transcendence central to Schneiders’ definition. In his later work, Hardy is careful to define spirituality in non-dualistic terms, not as something that removes us from life, but as something that enfleshes us in relationship to each other, the world, and the transcendent.<sup>41</sup> Thus, he understands sexuality to be an integral part of spirituality. In a further nuancing, the gay psychotherapist, John Fortunato, stresses meaning and community in his definition of spirituality. He defines the spiritual as “that aura around all of our lives that gives what we do meaning, the human striving toward meaning, the search for a sense of belonging.”<sup>42</sup> Finally, John McNeill emphasizes the notion of freedom in his definition. In his discussion of spirituality, he attempts to describe how, in seeking communion with the presence of the Spirit of God, in daily experiences, people are enabled to arrive at the

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<sup>39</sup> Ibid., 305.

<sup>40</sup> Richard P. Hardy, *Knowing the God of Compassion: Spirituality and Persons Living with AIDS*. Inner Journey Series (Ottawa: Novalis, 1993), 21.

<sup>41</sup> Richard P. Hardy, *Loving Men: Gay Partners, Spirituality and AIDS* (New York: Continuum, 1998), 19.

<sup>42</sup> John E. Fortunato, *AIDS: The Spiritual Dilemma* (San Francisco: Harper & Row, 1987), 8.

“glorious freedom” of the children of God.<sup>43</sup> McNeill pays careful attention to freedom of conscience and discernment of spirits in his discussion of spirituality.

Several elements of spirituality emerge from these definitions. First, spirituality assumes authenticity. These descriptions of spirituality consider the aspects of persons that allow them to be fully themselves. Second, spirituality involves integration around a core value or belief that provides life with meaning or purpose. Third, spirituality is relational – it is expressed in transcendence of self and a reaching toward the world and toward others. Fourth, a sense of freedom characterizes spirituality. Finally, there is a wholeness at the core of spirituality. Spirituality embraces all of human experience and being, including one’s body, one’s health, one’s sexuality and one’s memories.

In his treatment of AIDS and spirituality, Daniel A. Helminiak notes rightly that the spread of HIV has provoked a spiritual crisis. Several factors account for this characterization. First, HIV frequently affects people in the prime of life. Second, as a transmissible, terminal and stigmatized disease, AIDS is frightening. Third, life with AIDS and AIDS loss provokes large existential questions. Because these questions are questions of meaning and purpose, they may be understood as spiritual.

Another aspect of the spiritual crisis associated with AIDS was the early identification of AIDS with gay men described in Chapter 2. As such, AIDS was identified by some in the Christian church as God’s scourge upon them. Unfortunately, this unjust and unhappy characterization of AIDS served to undermine further the oppressive relationship that many gay and lesbian people have had with the Christian

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<sup>43</sup> John J. McNeill, *Freedom, Glorious Freedom: The Spiritual Journey to the Fullness of Life for Gays, Lesbians, and Everybody Else* (Boston: Beacon Press, 1995), xiii.

Church. As John McNeill notes, “the Church was usually the place where there was the greatest threat and the greatest demand for self-hatred and repression” for gay and lesbian people.<sup>44</sup> This demand for suppression of self continues today in many Christian communities and it is part of the climate that contributes to the suffering and stigmatization associated with AIDS and AIDS loss.

Fortunately, one fruit of the AIDS epidemic has been a blossoming of gay spirituality. John McNeill has rightly noted parallels between the coming out process and life with AIDS, both of which have contributed to this development of gay spirituality. In McNeill’s view, both coming out and living with AIDS require detachment from the world’s dominant values. Further, people experience a mourning process both in their life with AIDS and in the coming out process. As McNeill notes:

This spirit of detachment [cultivated through the coming out process] has become especially important during this period of the AIDS crisis. By deepening their spiritual life, gays can turn what they see as the curse of gayness, the curse of being in exile, into spiritual gold by realizing that in proportion as they are exiles in this world, they belong even more deeply to the Kingdom of God.<sup>45</sup>

The wisdom gained in coming out may thus be applied to the crisis of living with AIDS. This development has allowed gay men and lesbians to find some comfort in the very fact of their difference, viewing it as spiritually positive rather than as detrimental. Nevertheless, it is still incumbent on the churches to extend to gay and lesbian people unqualified love and acceptance. While there may be some benefits arising from appreciation of difference, they do not justify its continued condemnation!

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<sup>44</sup> McNeill, *Freedom*, 29.

<sup>45</sup> *Ibid.*, 63.

Two movements lie at the heart of a healthy spirituality for persons living with AIDS and AIDS loss. The first is the movement toward self-acceptance and the second is the movement toward self-transcendence.<sup>46</sup> The movement toward self-acceptance may begin with surrender. As Hardy notes, the diagnosis of AIDS, and I would add, the experience of AIDS loss result in feelings of powerlessness and impasse. To the extent that a person living with AIDS or AIDS loss decides not simply to subsist with the disease or loss, but to embrace the experience, then the way is open for the integration of the experience. In other words, healing in life with AIDS and AIDS loss results when one is fully open to the reality of the experience as a part of life. In coming to terms with AIDS and AIDS loss, many individuals have had an opportunity to rethink their values and to affirm themselves through deepened relationships, sobriety, and renewed ties with their family and religious community. Further, many individuals in the AIDS crisis have come to a more positive view of themselves through their faithfulness in caring for loved ones and through pride in the gay community's active response to the ravages of AIDS. Each of these contributions provides a basis for greater self acceptance and wholeness through the experience of AIDS and AIDS loss.

A second movement at the heart of the spirituality of AIDS and AIDS loss is the movement toward self-transcendence. This movement frequently grows out of the increased compassion that can accompany life with AIDS and AIDS loss. It also may arise from the impasse accompanying these experiences. As Hardy notes, resolution of

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<sup>46</sup> My understanding of self-transcendence includes experiences in which the self encounters something larger than the self which then enlarges the self. I include in this category the service of others. Self-transcendence also includes the experience of mystery or of union with a reality beyond oneself in art, music, worship, community, dreams or revelation. See C. E. Scott, "Self-Transcendence" in *Dictionary of Pastoral Care and Counseling*, ed. Rodney J. Hunter (Nashville: Abingdon, 1990), 1139.

the impasse associated with AIDS may involve venting rage toward God and the world, trying to see beauty in oneself and in the world or in living for others through activism or care giving. Each of these modes of responding to AIDS and AIDS loss is relational, for each provides a deeper encounter with God, the world and others. These responses exemplify a movement beyond a narrow self concern and an opening of the heart to others.

In his book, *Sometimes My Heart Goes Numb*, Charles Garfield, the founder of Shanti, describes the work of some extraordinary AIDS caregivers.<sup>47</sup> As he describes these people and their ministries of care, he identifies a number of practices that characterize a spirituality of AIDS care giving. They include loving, listening, accepting, serving, normalizing the abnormal, reciprocating in providing care, experiencing the transcendent, accepting one's limitations, telling the truth and taking care of oneself. These practices, essential in caring for those living with AIDS, are also essential in caring for those recovering from AIDS loss and lead to greater self acceptance and self-transcendence.

In her study of AIDS memoirs, Susan Henking describes the importance of another practice important to survivors, namely *creative resistance*. As she notes:

the autobiographical acts which are AIDS-related memoirs, when read together, call us to mourning, militancy *and* cultural production. . . . [They] remind us that mourning-- and memorialization-- are not simply the domain of hegemonic culture. Nor are they simply conservative. Rather, such efforts are key for those of us who resist stigma and who must construct

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<sup>47</sup> Charles A. Garfield, with Cindy Springer and Doris Ober, *Sometimes My Heart Goes Numb: Love and Caregiving in a Time of AIDS* (San Francisco: Jossey-Bass, 1995).

identities in the contexts of pluralism and domination.<sup>48</sup>

In Henking's view, AIDS memoirs and the AIDS Quilt move beyond the "statistical" to the "individual," reminding us of the multitudes who are gone and most importantly, reminding us that *each act of mourning is different*.<sup>49</sup> In a society which devalues difference, the very act of asserting the uniqueness of one's experience of loss may be viewed as a political act. Thus, the individual may offer his or her experience of loss for the benefit of society as a whole in a self-transcendent act of healing.

While the definitions of spirituality we have explored in the context of AIDS emphasize the humanist aspects of spirituality, it is important to remember that the experience of spirituality in AIDS can be understood in explicitly Christian terms. As such, the ultimate value governing self-transcendence is Trinitarian, as Schneiders noted above in her description of a uniquely Christian spirituality. Many persons living with AIDS and surviving AIDS loss derive meaning from an explicit relationship with God. At the core of Christian spirituality, as Hardy notes, is "the discovery and choice of the God manifested in Jesus Christ by the Spirit as one's ultimate value in integrating one's life. . . . This means that the whole of the person's life. . . is taken into the vision of the loving and compassionate God incarnate in Jesus Christ."<sup>50</sup> A healthy Christian spirituality, as Hardy notes, involves a relationship of mutuality with others, the world

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<sup>48</sup> Susan E. Henking, "The Legacies of AIDS: Religion and Mourning in AIDS-Related Memoirs," in *Spirituality and Community: Diversity in Lesbian and Gay Experience*. Gay Men's Issues in Religious Studies Series, vol. 5. Proceedings of the Gay Men's Issues in Religion Group, American Academy of Religion, San Francisco, Fall 1992, ed. J. Michael Clark and Michael L. Stemmeler (Las Colinas, Texas: Monument Press, 1994), 18 (original emphasis).

<sup>49</sup> Ibid., 20.

<sup>50</sup> Hardy, *Loving Men*, 27.

and with God. All of these relationships are grounded in the incarnate love of Jesus

Christ who calls us into friendship:

You are my friends if you do what I command you. I do not call you servants any longer, because the servant does not know what the master is doing; but I have called you friends, because I have made known to you everything that I have heard from my Father. . . . I am giving you these commands so that you may love one another. (John 15: 14-15, 17)

As we shall soon discover, one of the most important fruits of the experience of traumatic loss can be a transforming experience of God that results in a deeper acceptance of self. Further, this self-acceptance may lay the foundation for a deepened ability to accept others and for a longing for a more just and inclusive world. While the introduction of AIDS was characterized too often by intolerance, denial and exclusion, life with AIDS and AIDS loss has also given birth to concern, compassion, and hope.

In this chapter, therefore, we have explored the ways in which the experience of AIDS and AIDS loss have given rise to reconstructions of core theological concepts and have led to a deepened experience of life in God expressed in increased integration. This integration is characterized by greater self-acceptance and an increased capacity for self-transcendence. While these qualities of spirituality may be experienced in explicitly Christian terms, they cannot be reduced to them. The Spirit of God has interacted with the human spirit in many contexts, both inside and outside of the Church, in the midst of the AIDS epidemic. The varieties of new life that have resulted from these interactions are leading to a deepened sense of love and community.

Let us now turn to the historical account of loss in the Black Death pandemic of the fourteenth century. The broadened perspective we shall gain will provide additional resources for the construction of a theology and spirituality of AIDS loss.

## **Part II**

### **Historical Analysis**



## CHAPTER 5

### “TERROR BY NIGHT, ARROW BY DAY AND THE PLAGUE THAT STALKS IN DARKNESS” : THE FOURTEENTH CENTURY AND ITS PERILS

And there was in those days death without sorrow, marriage without affection, self-imposed penance, want without poverty, and flight without escape.<sup>1</sup>

The 14<sup>th</sup> century suffered so many “strange and great perils and adversities” (in the words of a contemporary) that its disorders cannot be traced to any one cause; they were the hoofprints of more than the four horsemen of St. John’s vision, which had now become seven – plague, wars, taxes, brigandage, bad government, insurrection, and schism in the Church. . . . Simply summarized by the Swiss historian, J.C.L.S. de Sisimondi, the 14<sup>th</sup> century was ‘a bad time for humanity.’<sup>2</sup>

‘Sin is necessary, but all shall be well.  
All shall be well; and all manner of things shall be well.’<sup>3</sup>

The purpose of this chapter and the next is to argue that the experiences Julian of Norwich had with the Black Death had a marked influence on the development of her theology and spirituality. A related purpose is to lay the foundation for a comparative understanding of multiple loss. My belief, based on my analysis of Julian’s context and her

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<sup>1</sup> James Tait, ed. “Chronica Johannis de Reading et Anonymi Cantuariensis, 1346-1367,” in *The Black Death*, ed. and trans. Rosemary Horrox, Manchester Medieval Sources Series (Manchester: Manchester University Press, 1994), 74.

<sup>2</sup> Barbara W. Tuchman, *A Distant Mirror: The Calamitous 14<sup>th</sup> Century* (New York: Ballantine Books, 1978), xiii-iv.

<sup>3</sup> Julian of Norwich, *Revelation of Love*, ed. and trans. John Skinner (New York: Doubleday, 1997), p. 55. For future reference, all chapter citations from the Skinner translation refer to the Long Text.

articulation of her vision, is that her life experience, theology and spirituality provide helpful counterpoints for contemporary survivors of AIDS loss. Since Julian's religious experiences arose in response to her experiences of plague loss, they offer a resource for contemporary survivors of AIDS loss. I shall first describe the discovery that led me to this awareness and then articulate the thesis that developed from my encounter with Julian's work.

As noted in Chapter One, I spent two years in the early nineties as a pastoral caregiver immersed in ministry to persons with HIV disease and to survivors of AIDS loss. My work with AIDS and HIV continued in Idaho where, in 1993, I served on the board of the Idaho AIDS Foundation. Throughout this period of time, I continued to work as a hospital chaplain and to wrestle with the significant theological challenges posed by my exposure to the enormity of AIDS loss.

Following these experiences, I returned for further graduate study, and in the course of a doctoral seminar on the writings of medieval women mystics, I encountered these words in Julian of Norwich's *Revelation of Love*:

But of all pains that lead to salvation, this pain is the most: to see your love suffer. How might any pain be more to me than to see him who is my whole life, my bliss and all my joy suffer? Here I truly felt that I loved Christ so much above myself that there was no worse pain I might suffer than to see him in pain.<sup>4</sup>

Julian uttered these words while viewing a vision of Christ's suffering and death on the cross.

When I read these words, I became galvanized. They reminded me instantly of sentiments expressed by partners, family members and friends of those who died with

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<sup>4</sup> Julian, *Revelation*, 38-39.

AIDS. Further, they brought to mind my own pain in witnessing the deaths of friends and family members. In short, they articulated the perspective of a survivor. I knew upon reading them that Julian was well-acquainted with death, and in that moment I became curious about her. Who was she and how had she come to express this compassion for suffering so clearly? My attempt to answer these questions precipitated a search that finally led to the understanding of Julian and her context presented in this chapter. Further, it led to the thesis that I shall advance in this chapter and elaborate in the next. The thesis is that *Julian may be understood as a survivor of multiple loss arising from the plague*. I believe that Julian's experience of plague loss shaped both the form and effects of her religious experience, including her vision, and may also have motivated her to articulate and disseminate her theological reflections upon it at some personal risk.

If my hunch is right, two convictions flow from it. First, I believe that the experience of plague loss beginning in the mid-fourteenth century offers a significant experience of multiple loss that can rightly be compared with AIDS-related multiple loss. Second, elucidating Julian's theology in the context of plague loss offers promise for understanding the contemporary experience of AIDS loss. As I noted above, I believe that studying Julian and her time has much to offer to a contemporary analysis of AIDS, because exploring plague loss and its effects should highlight common features of multiple loss, place unique aspects of plague and AIDS loss in relief, clarify cultural aspects of the experience of multiple loss and suggest important psychological and theological themes to consider in the exploration of AIDS loss.

The present chapter, therefore, will proceed as follows. First, we shall explore certain particulars about Julian's life, as well as the wider historical and religious context that shaped it and formed her distinctive theological vision. Second, we shall examine, in particular, the experience of the Black Death as a key influence in the development of Julian's thought. Finally, the analysis will attend to the extent of plague loss, its social effects, the religious response to it, the phenomenal experience of plague loss, pastoral concerns raised by the plague, and the dominant theological interpretations offered in Julian's day. In the next chapter, I shall attempt to characterize Julian as a survivor of plague loss and to explore how the psychological understanding of survivors advanced by Robert Lifton may help to elucidate Julian's life experience. Further, we shall turn specifically to her theology and spirituality in an attempt to understand them in relationship to the dominant theology of her day and in relationship to her experience as a plague survivor.

### **Julian's Life and Times**

The first step in understanding Julian's creative theology and distinctive spirituality is to view them against the backdrop of fourteenth century British life. We begin with the awareness that death was both an omnipresent and "grim business" in the Middle Ages.<sup>5</sup> Julian's time was violent and brutal, characterized by cruel warfare, brigandage, the torture and persecution of Jews, and extremes of destructive piety. The latter included the masochistic rites of the flagellants and the fiery execution of convicted heretics, including the Lollards of Julian's own Norwich. Undoubtedly, the ever-present

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<sup>5</sup> T. S. R. Boase, *Death in the Middle Ages: Mortality, Judgment, and Remembrance*, ed. Joan Evans and Christopher Brooke, Library of Medieval Civilization (London: Thames & Hudson, 1972), 9.

reality of violence, in conjunction with the ecological instability revealed in recurring famines and plagues, accounts for the oft grotesque fascination with death expressed in fourteenth century art. Ironically, in view of these realities, the well-developed penitential system and eschatological teachings about the Great Judgment and the afterlife, that were intended to provide comfort to penitents, further heightened the anxieties about salvation. As we shall see, Julian placed her primary emphasis upon questions of salvation and her focus on these concerns is quite representative of her age. In many ways, Julian lived in a transitional time, a day in which the “insistent principle that the life of the spirit and of the afterworld was superior to the here and now” was giving way to “a belief in the worth of the individual and of an active life not necessarily focused on God.”<sup>6</sup> If anything, this shift may have heightened the concern with individual salvation. The roots of this change in mindset lay within the Church and its associated institutions, including the papacy and the university. The former was noted in Julian’s day for its corruption and lavish extravagance, and the latter for new philosophies such as nominalism that were laying the groundwork for the development of a more secular world view. Each contributed in its own way to the decline of the medieval world’s grand synthesis.

We know few things for certain about Julian and her life. She tells us in her text that she experienced her life-changing vision on the eighth day of May in 1373 when she

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<sup>6</sup> Tuchman, *Distant Mirror*, xix.

was thirty and a half years old.<sup>7</sup> From this we can infer that Julian was born close to the end of 1342. A bequest by Roger Reed, rector of St. Michael's Church at Coslany in 1393 to "Julian anakorite" suggests that Julian had adopted the distinctive lifestyle of an anchoress by that time. That she continued in this ministry into the next century is supported by the prologue to the short text identifying her as "a recluse at Norwich living yet in 1413."<sup>8</sup> Evidence from wills hints that Julian lived to be at least seventy-four years old.<sup>9</sup> Two bequests, one in November, 1415 by John Plumpton for forty pence to "the ankeres in ecclesia sancti Juliani de Conesford in Norwice," and another in 1416 by Isabelle Ufford, Countess of Suffolk to support Julian, suggest that Julian lived to a ripe old age.<sup>10</sup> The testimony of the flamboyant Margery Kempe, a contemporary of Julian's from nearby King's Lynn, suggests that Julian's reputation as a spiritual counselor was well-established, as Margery refers to her as "an expert in such things [who] could give

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<sup>7</sup> Julian, *Revelation*, 4. However, as Grace Jantzen notes in *Julian of Norwich: Mystic and Theologian* (London: SPCK, 1987), 13, n. 10, variant readings in the manuscripts of Julian's work have yielded some uncertainty about this date. According to Jantzen, Colledge and Walsh, editors of the critical edition of Julian's work, follow the Paris manuscript and set the date at May 13 (xiiij), whereas other authorities including Skinner and Jantzen follow the Sloane manuscript's viij. According to Brant Pelphrey in *Love Was His Meaning: The Theology and Mysticism of Julian of Norwich* (Salzburg: Institut für Anglistik und Amerikanistik, Universität Salzburg, 1982), 1, n. 1, Julian's reference to the Passion and to Easter implied in her visions yields a preference for the May 8<sup>th</sup> date, as this fell on the third Sunday after Easter in 1373.

<sup>8</sup> Julian of Norwich, *A Shewing of God's Love*, ed. Anna Maria Reynolds (London: Sheed & Ward, 1958), lviii. For future reference, quotations from Reynolds are from the Short Text.

<sup>9</sup> However, as Jantzen, *Julian of Norwich*, 20 correctly observes, this evidence is not definitive, since "Julian" was a common name at this time. In addition, it was the practice for anchoresses to adopt their name from the church in which their cell was located. Therefore, it is theoretically possible that this bequest was for another anchoress named Julian who resided at the Church of St. Julian at Conisford, a Saxon-Norman church on the Wensum river. However, most scholars assume given the dates associated with the manuscripts and Julian's vision that it is indeed plausible that this bequest was made to the anchoress we know as the author of the *Revelations*.

<sup>10</sup> Jantzen, *Julian of Norwich*, 21.

good advice.”<sup>11</sup> In fact, scholars have commented on the congruity between the advice Margery received and the theology of Julian’s text, supporting the view that the anchoress Margery consulted was the author of the *Revelations*.<sup>12</sup>

Aside from this “external” data about Julian’s life, we can glean other critical information from Julian’s texts. Julian’s *Revelations* exist in two versions, popularly described as the Short and Long Text. These texts are found in several manuscripts. Four of them are held in the British library. These holdings include Additional 37790, a mid-fifteenth century version of the Short Text known as “Amherst”; and three mid-seventeenth century versions of the Long Text: Sloane 2499; Sloane 3705; and Stowe 42. In addition, the earliest version of the long text, Anglais 40, dating from the sixteenth century, resides at the Bibliotheque Nationale in Paris. Finally, Westminster Cathedral owns the second oldest version of the Short Text, dating from around 1500.

Baker rightly raises the question posed by other Julian scholars: “Is the short text in Amherst, the earliest extant manuscript, an abridgement of or an antecedent to the long text witnessed by the remaining five documents?”<sup>13</sup> Did Julian compose both documents, and if so, when did she write them?

Most scholars, following Edmund Colledge and James Walsh, editors of the critical edition in Middle English, believe that Julian composed both versions herself and that the Short Text preceded the Long Text by twenty or more years. If we assume that

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<sup>11</sup> Margery Kempe, *The Book of Margery Kempe*, trans. B. A. Windeatt, rev. ed. (New York: Penguin, 1994), 77.

<sup>12</sup> See, for example, Pelphrey, *Love Was His Meaning*, 12.

<sup>13</sup> Baker, Denise Nowakowski, *Julian of Norwich’s Showings: From Vision to Book* (Princeton: Princeton University Press, 1994), 4.

Julian wrote the Short Text soon after her vision in 1373, and further assume, based on her own words, that she reflected on the Vision of the Lord and Servant for twenty years before including it in the Long Text, then the earliest possible date for the Long Text is 1393.<sup>14</sup>

In summary, therefore, we can conclude with some certainty that a devout anchoress known as Julian had a series of life-changing visions focused primarily, but not exclusively, on Christ's crucifixion. Further, she wrote two accounts of her visions: a short version assumed to be written soon after the event and a second longer version written after nearly twenty years of sustained reflection on it. Aside from this, it is difficult to establish with certainty Julian's marital status, religious vocation, social class, and level of education, despite the fact that a plethora of theories have been advanced about these more personal details of her life.<sup>15</sup> Wherever possible, and as they become pertinent to the present argument, I shall reveal my own views on these matters.

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<sup>14</sup> Minority opinions are offered by Nicholas Watson and Julia Bolton Holloway. Watson believes that the Amherst manuscript reflects the greater anxiety of the period closer to 1413 when Archbishop Arundel of Norwich, in response to the Wycliffites, was prohibiting lay people, especially women, from teaching theology. He suggests that the Long Text was written later than the Short Text when Julian would have been 85 or 90. In contrast, Holloway agrees that the Short Text is late, but argues that the Long Text's traditional date of approximately 1373 is right, thus reversing the order of composition, and assuming that the Short Text is composed after the long text. See Nicholas Watson, "The Composition of Julian of Norwich's *Revelation of Love*," *Speculum* 68 (1993): 637-83, and "Censorship and Cultural Change in Late-Medieval England: Vernacular Theology, the Oxford Translation Debate, and Arundel's Constitutions of 1409," *Speculum* 70 (1995): 822-64; and Julia Bolton Holloway, "Anchoress and Cardinal: Julian of Norwich and Adam Easton, O.S.B., lecture delivered at Norwich Cathedral, Norwich, England, 1 December 1998.

<sup>15</sup> For a lively account of Julian's background see Sheila Upjohn, *In Search of Julian of Norwich* (London: Darton, Longman & Todd, 1989). Theories about Julian's level of education, in particular, abound. On the one hand, Colledge and Walsh believe that Julian was "a master of rhetorical art to merit comparison with Chaucer" who was well versed in the Latin Vulgate and familiar with the foundational texts of the monastic contemplative tradition of the Western Church. See Julian of Norwich, *Showings*, trans. Edmund Colledge and James Walsh (New York: Paulist Press, 1978), 19-21. On the other hand, Brant Pelphrey suggests that Julian may have been uneducated, possessing only rudimentary literary skills, and may have composed her text with the help of a scribe. Like Jantzen, *Julian of Norwich*, 15-20, I would argue that the truth falls somewhere in between these two extremes.



As intriguing as speculation about these matters may be, perhaps the most significant fact about Julian's life for our purposes was that it was marked by a series of outbreaks of the plague. The first and most serious one occurred when she was just six years old. This epidemic constituted one of the greatest disasters the Western world has experienced. Besides this initial outbreak, Julian also survived additional plague epidemics, including those in 1361 and 1369. While we cannot be certain that Julian was living in Norwich at this time, we do know that wherever she was living in England, she would have experienced the plague. Further, we can also assume that the amount of suffering the people in Norwich experienced as a result of the plague would not be soon forgotten. As we shall see, this factor would surely have influenced the ministry of spiritual care that Julian exercised later in her life. Further, the effects of this suffering only seem magnified when plague-induced suffering is explored in relation to other key events of Julian's day. Therefore, we turn to a brief exploration of the religious and political climate of fourteenth century Norwich, especially as these shaped the turbulent context in which the fourteenth century experience of the plague was mediated.

### **The Religious and Political Context of Fourteenth Century Norwich**

The fourteenth century in which Julian lived and wrote was a time characterized by the best and worst of human achievement. On the one hand, the age was distinguished by religious and artistic genius. Julian's contemporaries in the literary realm include such towering figures as Petrarch, Boccaccio, Chaucer and Langland. In addition, the religious realm in her time experienced one of the greatest flowerings of mystical piety known in a comparable period. England alone experienced the work of

Walter Hilton (1396), the anonymous author of *The Cloud of Unknowing*, and the writings of Richard Rolle (1300-1349) and Margery Kempe (1373-1439). Continental mystics included many significant women: Birgitta of Sweden (1303-1373) and Catherine of Siena (1347-1380) are the most well known, but other contemporary and near contemporay women religious writers include Mechtild of Magdeburg (1212-1299), Mechtilde of Hackeborn (1310), Gertrude of Helfta (1256-1311), Angela of Foligno (1248-1309), and Margaret Ebner (1291-1351).<sup>16</sup> Male continental mystics active at this same time included such giants as Jan van Ruysboreck (1293-1381), Jean Gerson ( 1363-1429), Meister Eckhardt (1260-1327), John Tauler (1300-1361) and Henry Suso (1295-1365).

Despite the towering accomplishments of these figures and the energy and vibrancy associated with them, the fourteenth century was also marked by a great discrepancy between its moral and philosophical ideals and the behavior that these ideals were intended to guide. Barbara Tuchman expresses this most clearly in her evaluation of the failure of the chivalric ideal: "if the [chivalric] code was but a veneer over violence, greed and sensuality, it was nevertheless an ideal, as Christianity was an ideal, toward which man's reach, as usual, exceeded his grasp."<sup>17</sup> This failure of ideals captures the essence of the period, and the failure was exacerbated by what Tuchman refers to as the four scourges of the century: war, the companies of brigands who fomented violence and lawlessness, papal schism, and plague. Each of these realities contributed to the

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<sup>16</sup> I am indebted to Pelphrey, *Love Was His Meaning*, 41 for this list of figures.

<sup>17</sup> Tuchman, *Distant Mirror*, 69.

dissolution of medieval ideals and the eventual re-creation of secular and religious society experienced in the Renaissance and Reformation.

The city of Norwich was not insulated from the best and worst of the time; in Julian's day, the city had a prominence that far exceeds its current status. In the late fourteenth century, Norwich was the second largest city in England, and it was a thriving center for shipping and for cloth trade. Its prominence was due, in part, to geography, combined with a harsh political reality. Norwich was an inland port situated on the river Wensum and was handily positioned for trade with England's economic partners in Flanders and the Rhineland. This protected location gave it an economic boost as wartime raids on Southern English ports caused the diversion of traffic to Norwich.

This economic and geographical prominence also led to an intellectual trade, as Grace Jantzen aptly notes.<sup>18</sup> The exchange of religious ideas between Norwich and the continent may have been responsible for such innovations as a house of beguines in Norwich, the only one in England, and the existence of a full array of religious communities in the city, including Benedictines, Dominicans, Franciscans and Augustinians.

Studies of the religious climate of fourteenth century Norwich highlight the existence of a thriving religious life. Even today, tangible evidence remains in the form of the many medieval parish churches that dot the city. Norman Tanner notes that Norwich possessed forty-six parish churches in the late medieval period and was second only to London in this number. Of course, in Julian's day, the Norman cathedral and its

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<sup>18</sup> Jantzen, *Julian of Norwich*, 7.

Benedictine priory were at the geographical and spiritual heart of the city. Construction of this impressive and breathtakingly beautiful structure was begun in 1097 by Herbert Losinga, the first Bishop of Norwich. Besides providing a focus for the spiritual life, the cathedral provided a focus for artistry and craftsmanship in the city. Forty-six guilds and religious confraternities thrived in the city in Julian's day, and the cathedral's beauty undoubtedly benefited from the wealth of artisans and craftsmen who plied their trade in Norwich.

Tanner, along with Roberta Gilchrist and Marilyn Oliva, provides evidence for a dynamic religious culture in Norwich in the late medieval period.<sup>19</sup> In Tanner's view, the older and more clerical aspects of the church in Norwich continued to thrive. At the same time, the city was enriched by the presence of new religious movements which arose in the late medieval period and were largely directed toward the laity.<sup>20</sup> These included: the proliferation of religious lifestyles, including hermits, anchorites and groups resembling beguinages; craft guilds and their associated guild-days, processions and mystery plays; pious confraternities; pilgrimages and devotions to the saints; improvements in the religious education of the laity; and the multiplication of Masses and prayers for the dead.<sup>21</sup> In fact, both Tanner and Gilchrist and Oliva provide helpful and concrete information supporting the notion that alternative religious lifestyles thrived in Norwich.

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<sup>19</sup> Norman P. Tanner, *The Church in Late Medieval Norwich, 1370-1532* (Toronto: Pontifical Institute of Medieval Studies, 1984); Roberta Gilchrist and Marilyn Oliva, *Religious Women in Medieval East Anglia: History and Archaeology*, Studies in East Anglian History, 1 (Norwich, England: Centre of East Anglian Studies, University of East Anglia, 1993).

<sup>20</sup> Tanner, *Church in Late Medieval Norwich*, 167.

<sup>21</sup> *Ibid.*, 168.

As Tanner notes, more hermits and anchorites appear to have been living in Norwich in the fifteenth and early sixteenth centuries than in any other town in England.<sup>22</sup> One wonders, what effect, if any, Julian's renown had in influencing this trend.

Gilchrist and Oliva's study of religious women in East Anglia makes it clear that women as well as men participated in these movements. In fact, they conclude that the preponderance of religious women of various sorts in Norfolk and Suffolk support the conclusion that laity in this region were active participants and generous supporters of a lively religious life. They identify at least six categories of religious women in East Anglia at this time, including nuns, hospital sisters, and women who lived in informal religious communities, anchoresses, vowesses and other religious women who lived singly but whose particular status was uncertain. They conclude that the female piety associated with these vocations greatly enriched the local community. A particularly interesting finding is their evidence that communities of religious women, in contrast to communities of men, were never intended to be self-supporting; thus, they existed in a more interdependent relationship with the local community, benefiting from their gifts and favors as they shared prayers and charitable works of mercy with those in need.

While this evidence provides an optimistic picture of the health of religious institutions in Norwich, there are indications that dissent and disillusionment with the Church were not unknown, by any means. Factors contributing to dissatisfaction with the institutional Church are several and include the nature of the papacy in the fourteenth century, the leadership of Bishop Henry Despenser, and the presence of Wycliff sympathizers in Norwich.

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<sup>22</sup> Ibid., 169

The greatest source of discontent with the Church in Julian's day may be attributed to scandals associated with the papacy. Relations between the papacy and state in the fourteenth century began badly with the assault on Pope Boniface VIII by agents of Philip IV, King of France, in 1303. The issue at stake was temporal versus papal authority: Philip wanted to tax clerical income without support from the Pope. Boniface forbade the clergy from complying, fearful that clerics might develop greater allegiance to the king than the pope. In the Bull, *Unam Sanctum* in 1302, Boniface boldly asserted, "It is necessary to salvation that every human creature be subject to the Roman pontiff."<sup>23</sup> Needless to say, Philip did not respond well to this pronouncement. He called for a council to judge the pope on charges of heresy, blasphemy, murder, sodomy, simony and sorcery, and failure to fast on feast days; Boniface, in return, excommunicated him. Philip's response was to seize the pope at his summer estate in Anagni in an attempt to delay the excommunication and bring the Pope before a council. While he was quickly freed by local citizens, the Pope soon died from the shock of these events.<sup>24</sup>

One consequence of this unfortunate situation was the eventual movement of the papacy from Rome to Avignon. Under Philip's influence a French pope was elected in the person of Clement V. Because he feared reprisal from the Romans and, some say, separation from his French mistress, Clement chose to reside in Avignon. The next six popes in succession, following in Clement's footsteps, chose to reside in Avignon. As Tuchman sagely notes in her commentary on these events:

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<sup>23</sup> Tuchman, *Distant Mirror*, 25.

<sup>24</sup> *Ibid.*, 25

Diminished by its removal from the Holy See of Rome and by being generally regarded as a tool of France, the papacy sought to make up prestige and power in temporal terms. It concentrated on finance and the organization and centralization of every process of papal government that could bring in revenue. Besides its regular revenue from tithes and annates on ecclesiastical income and from dues on papal fiefs, every office, every nomination, every appointment or preferment, every dispensation of the rules, every judgment of the Rota or adjudication of a claim, every pardon, indulgence and absolution, everything the Church had or was, from cardinal's hat to pilgrim's relic was for sale.<sup>25</sup>

Other sources of papal income included benefices, payments to avoid excommunication and anathema, and dispensations of every sort. Petrarch aptly captured the irony of the situation when he noted that the popes, "successors of the poor fishermen of Galilee," were now "loaded with gold and clad in purple."<sup>26</sup>

English views on the Avignon papacy were, of course, jaded and undermined by the political tensions between France and England during this period. As Tuchman notes:

In England they had a saying, 'The Pope has become French and Jesus English.' The English were increasingly resentful of the papal appointment of foreigners to English benefices, with its accompanying drain of English money outside the country. In their growing spirit of independence, they were already moving toward a Church of England without being aware of it.<sup>27</sup>

Further, corruption and greed were not limited to the papacy as "corruption spread through the hierarchy from canons and priors to priesthood and cloistered clergy, down to mendicant friars and pardoners."<sup>28</sup> Reviewing the list of papal and clerical abuses calls to mind Julian's observation that "God's servants, that is to say holy Church shall be shaken in sorrow and anguish and tribulation in this world, just as people shake a cloth in

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<sup>25</sup> Ibid., 26.

<sup>26</sup> Ibid., 28.

<sup>27</sup> Ibid., 250.

<sup>28</sup> Ibid., 30.

the wind.”<sup>29</sup> As the century wore on, the problems of the papacy culminated in the Great Schism, the election of two competing popes, one based in Rome and the other in Avignon in 1378. The existence of the schism had nothing to do with questions of doctrine; rather, it resulted from the complex political alliances between Church and state. The scandal of two competing popes was compounded in 1409 with the election of a third, and the papal schism was not to be resolved until the end of the eighteen year long Council of Basle in 1449. As a result, the power and prestige of the papacy was considerably diminished, paving the way for the Protestant Reformation that was soon to follow.

While Norwich was at some remove from both Avignon and Rome, the rivalry between competing claimants for the papal throne came quite close to home for Julian and her fellow citizens. This state of affairs resulted from the deplorable actions of Henry Despenser, who served as Bishop of Norwich from 1370 until 1406. Despenser, described by the chronicler Thomas Walsingham as “young unbridled and insolent...endowed neither with learning nor discretion, experienced neither in preserving nor bestowing friendship,” became known for two ruthless acts.<sup>30</sup> The first was his cruel suppression of the Peasant’s Revolt in 1381, a violent uprising due, in part, to labor shortages resulting from the plague. The second was his organization, promotion and oversight of a “crusade” in 1383 against the French and Flemish supporters of Pope

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<sup>29</sup> Julian of Norwich, *Revelation of Love*, Chap. 28, 56.

<sup>30</sup> Tuchman, *Distant Mirror*, 403.



Clement VII on behalf of Pope Urban VI. Tuchman colorfully and ironically describes this ill-conceived military operation.

It began in scandal and was to end in fiasco. The moral harm done to papal obedience in England by the methods of financing the 'crusade' outweighed anything the papacy could have gained, even with success. Friars as papal agents were endowed with 'wonderful indulgences' and extra powers to sell, or worse, to refuse absolution 'unless the people gave according to their ability and estate.' Even the sacrament was at times withheld from parishioners who refused an offering to the crusade. Gold, silver, jewels and money were collected especially, according to Knighton, from 'ladies and other women. . . . Thus the secret treasure of the realm, which was in the hands of women, was drawn out.'<sup>31</sup>

The first consequence of the war was protest in England by the Lollards. The second equally significant result was the disgraceful outcome of the "crusade." Upon landing in Calais, Despenser and his troops experienced some initial victories against the Flemish. When they were overcome in the fields in Northern France by a greatly superior French force, however, the Bishop's men deserted him in battle. Thereupon, he beat a hasty retreat to Bourbourg where he remained for several months, until the war was concluded by a negotiated settlement, as the French had no desire to fight. The Bishop left with no gain or glory to show for his efforts: as Tuchman notes, "he was bought off and went home to deficit and disgrace."<sup>32</sup> While it is certainly difficult to fathom fully the sentiments about the Bishop's behavior 600 years later, every indication suggests that he had little support for his ruthless militarism. The overwhelming impression of the Great Schism is that it was scandalous to the faithful and perplexing even to those most

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<sup>31</sup> Ibid., 402.

<sup>32</sup> Ibid., 403.

responsible for its occurrence. That many would see a military operation as the preferred solution seems doubtful.

The presence of the Lollards constitutes the third clear source of evidence for religious dissent in Julian's day. The name "Lollards" was given to a group of religious dissenters whose views were in sympathy, in many respects, with those promulgated by John Wyclif, the noted Oxford preacher, scholar and posthumously condemned heretic.<sup>33</sup> Like Wyclif, the Lollards attacked clericalism and religious abuses, denied transubstantiation and promoted the translation and reading of the Bible in English. Further, they were devoted to the humanity of Jesus. Known for their heterodoxy, they are also associated with the unrest of the Peasants' Revolt of 1381 and with the Oldcastle uprising in 1414. Thus, the movement represented both a religious and civil threat, and as Tuchman notes, its primary sympathizers were drawn from the commoners and lower clergy. From 1385 onwards, Lollards were persecuted in England, and in 1398, the Bishops requested authorization of the death penalty against them. According to Tanner, Lollardy never gained the prominence in Norwich that it achieved in other centers, such as London; however, at least three Lollards were burned in Norwich in 1428. Numerous other Lollard sympathizers were sentenced to be flogged or to do "solemn penance" in the city.<sup>34</sup> Therefore, Julian would undoubtedly have been aware of the current of dissent associated with Lollardy, and scholars have suggested that she may have consciously

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<sup>33</sup> Jantzen, *Julian of Norwich*, 10 provides three possible origins for the term "lollard": she notes it is a term "derived from a combination of a Middle Dutch word meaning 'a mumblor of prayers,' and a Middle English word meaning 'loafer,' and made even more abusive by a pun with the Latin 'lolia' which means 'tares.'"

<sup>34</sup> See Tanner, *Church in Late Medieval Norwich*, 165-66.

framed several of the disclaimers present in her text to distinguish herself from its adherents. These may explain her remarks in the Short Text in which she discounts her authority as teacher:

But God forbid that ye should say or take it thus, that I am a teacher  
for I do not mean that, nor meant I ever so. For I am a woman,  
unlettered, feeble and frail.<sup>35</sup>

A second, potential influence may be reflected in the care she takes to indicate that there is nothing in her vision that draws her away from the teaching of the Church.

Although the revelation treated of goodness, with little mention of evil,  
yet I was not drawn away from it by any single detail of the faith that  
holy Church teaches me to hold. . . . And I was strengthened and taught in  
general to keep my faith in every detail and in all I had understood before,  
hoping in this way that I was held in the mercy and grace of God, only  
wishing and praying in my every intention that I might continue in such  
way to my life's end.<sup>36</sup>

A final factor significantly shaping life in medieval Norwich and throughout Western Europe, the Hundred Years War between France and England, raged off and on from 1337 to 1453. Its cause was two-fold: first, England claimed territory in lower Western France in Guienne and Gascony, remnants of the inheritance of Henry II through Eleanor of Aquitaine. Second, Edward III, King of England from 1327- 1377, launched a claim to the throne of France through his mother's line. This war exerted its effects in several ways. First, it provided a severe drain of money and manpower on England throughout its course, but particularly from the mid-fourteenth century on, when England's earlier military successes were reversed. Second, the war encouraged the

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<sup>35</sup> Julian of Norwich, *Shewing of God's Love*, 17.

<sup>36</sup> Julian of Norwich, *Revelation of Love*, 57.

development of a climate of lawlessness. English troops learned to survive on the plunder of war in France, and once they returned home, “they robbed and assaulted travelers, took captives, held villages for ransom, killed, mutilated and spread terror.”<sup>37</sup> Finally, the war contributed to the death of ideals to which we have already alluded: it severed the chivalric code that had united the nobility and created a climate of mutual antagonism between England and France that was to last for centuries. The war, in combination with the Great Schism, contributed to the growing climate of nationalism and the rise of the nation-states. Throughout Julian’s lifetime, under a variety of monarchs, England was at war with France, Scotland and Wales. Many of those who sought Julian out for counseling may have been touched by the pain of wartime losses.

As this survey of the century’s climate demonstrates, Julian lived at an intellectual, moral, and religious crossroad. While, in many cases, the structures of medieval life continued to flourish, the social and theological underpinnings supporting them were corroding through violence, greed, excess and the disillusionment associated with suffering. Medieval unity increasingly gave way to a concern with autonomy, whether of church, state or individuals. While social and religious factors exerted their influence on this changing climate, natural conditions played an equally important role. The effect of these various changes was a profound cynicism in many quarters, and that was writ large. God’s disapproval, considered as a cause of suffering, seemed

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<sup>37</sup> Tuchman, *Distant Mirror*, 195.

synonymous with this human pessimism. Julian lived, prayed and wrote in this gloomy climate, and we shall see how her distinctive voice offered a creative alternative to the currents of disillusionment so prevalent in her day.

### **The Black Death in Fourteenth Century Europe**

The arrival of the “pestilence” or “Great Mortality” in fourteenth century Asia heralded one of the greatest disasters ever known. The plague, arriving in Europe from the East, was spread primarily through well-established trade routes from parts of Eurasia where it was endemic. One of the most chilling accounts of its anticipated arrival was recorded by an Irish chronicler.

And I, Brother John Clynn, of the Friars Minor of Kilkenny, have written in this book the notable events which befell in my time, which I saw for myself or have learnt from men worthy of belief. So that notable deeds should not perish with time, and be lost from the memory of future generations, I, seeing these many ills, and that the whole world is encompassed by evil, waiting among the dead for death to come, have committed to writing what I have truly heard and examined, and so that the writing does not perish with the writer, or the work fail with the workman, I leave parchment for continuing the work, in case anyone should still be alive in the future and any son of Adam can escape this pestilence and continue the work thus begun.<sup>38</sup>

Two features of this account are noteworthy: first, Clynn’s impression that death from the plague might be total and, second, the frightening sense he had of “waiting among the dead for death to come.” To contemporary chroniclers, the first plague epidemic seemed to be a harbinger of the world’s end. Waiting for what appeared to many to be certain death must have created an ominous sense of doom, indeed.

This sense of impending disaster was clearly grounded in real and massive mortality. As Horrox notes, historians have tended to be of two minds about the plague

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<sup>38</sup> Richard Butler, ed., “Annalium Hibernae Chronicon,” Irish Archaeological Society, 1849, 37 in Horrox, *Black Death*, 84.

and its effects. Late nineteenth century historians, such as Cardinal Gasquet, believed that the plague “wrought cataclysmic change, not only in society but within the individual.”<sup>39</sup> These historians postulated grand and sweeping effects of the plague and attributed the decline of medieval certainty to the plague’s devastation. Succeeding generations of historians, however, tended to downplay the effect of the Black Death. Their cynicism is reflected in Bean’s observation that “the removal of cataclysms is almost an occupational disease of modern historians” because critical approaches lead to suspicion about the consequences of great events [and] of the work of professional colleagues whose reputations are based on the discovery of crises.<sup>40</sup> Cynicism aside, Horrox notes that recent trends in scholarship are tending towards increased acceptance of the notion that plague mortality was much higher than historians believed in the 1970s. At that time, the figure of a third was normative; however, historians now believe that mortality, particularly in some areas, may have been considerably greater.

Many medieval estimates of mortality are indeed suspect, but they are testimony to a sense of dislocation and shock which it is unduly (and offensively) arrogant to ignore, whatever the actual mortality levels may have been. In recent years English assessments of the mortality in 1348-49 have also been rising steadily back towards a death rate of almost one in two, providing a context in which any contemporary exaggeration seems entirely understandable.<sup>41</sup>

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<sup>39</sup> Horrox, *Black Death*, 229.

<sup>40</sup> J. M. W. Bean, “The Black Death: The Crisis and Its Social and Economic Consequences,” in *The Impact of the Fourteenth Century Plague*, ed. Daniel Williman (Binghampton, N.Y.: Center for Medieval and Early Renaissance Studies, 1982), 23; quoted in Philip Lindley, “The Black Death and English Art: A Debate and Some Assumptions,” in *The Black Death in England*, ed. Mark Ormrod and Phillip Lindley, (Stamford, Lincolnshire, England: Paul Watkins, 1996), 136, n. 51.

<sup>41</sup> Horrox, *Black Death*, 234.

Thus, estimates of plague mortality have risen from thirty percent in the 1970s to forty percent in the early 1980s to an average mortality of 47 to 48 percent today. These estimates are based on an increasing number of local studies that allow for more precise estimates of plague death in a given region.

As Tuchman notes, Western Europe had heard rumors of a terrible plague arising in China and spreading to India, Persia, Mesopotamia, Syria, Egypt, and Asia Minor as early as 1346.<sup>42</sup> However, the threat of death did not clearly emerge until the plague made its entry into the Sicilian port of Messina in October, 1347. It arrived through Genoese trading ships returning from the Black Sea port of Caffa in the Crimea. According to the traditional account of the Piacenzan chronicler, Gabriele de Mussis, Italian merchants became infected in a war in Caffa waged against them by the Tartars. When plague broke out in their army, the Tartars reportedly loaded plague victims on catapults and launched them over the walls of Caffa, infecting the citizens and merchants. Fleeing “what seemed like mountains of dead,” the merchants sailed for Sicily, and arrived with dead and dying men at the oars.<sup>43</sup> Within a few days, the plague spread widely in Messina, and from there, it quickly infected all of Sicily. From Sicily, it progressed to North Africa by way of Tunis, to Corsica and Sardinia, to Balearics,

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<sup>42</sup> Tuchman, *Distant Mirror*, 93. Robert S. Gottfried gives a full account of the hypothesized origin of the plague in the East and its spread through Eurasia in *The Black Death: Natural and Human Disaster in Medieval Europe* (New York: Free Press, 1983), 33-42.

<sup>43</sup> A.W. Henschel, “Document zur Geschichte des schwarzen Todes,” in *Archiv für die gesamte Medicin*, ed. Heinrich Haeser, II, Jena, 1841, in Horrox, *The Black Death*, 17.

Almeria, Valencia and Barcelona, and then to Southern Italy. As Ziegler notes, bubonic plague closely followed the main trade routes in its spread.<sup>44</sup>

The spread of the plague, once it entered the European mainland, was rapid and relentless. It spread from Italy to the Holy Roman Empire within a year. It reached Bavaria by June 1348 and Austria by November of that year. It reached Vienna and Northern Germany in 1349. The plague apparently spread to the western Mediterranean coast through Italian sailing ships. It entered France through coastal towns and then infected Avignon in the spring of 1348 and Paris in June of 1348. Death rates were stunning: between February and May, up to 400 people a day died in Avignon. As Gottfried notes, in Avignon in one six week period, 11,000 people were buried in a single graveyard, one out of three cardinals died, and the total mortality likely exceeded 50 percent.<sup>45</sup> Paris, the largest city of Northern Europe with a population of between 80,000 and 200,000, experienced 800 deaths per day in November and December.<sup>46</sup>

At the same time as it was moving northward, the plague also moved to the West. It passed through Toulouse to Bordeaux and probably traveled from Gascony in Western France to England in the summer of 1348. Accounts of the port of entry differ, with Bristol, Melcombe and Southampton as likely candidates, but, however it arrived, the plague reached London by the fall of 1348. England was extremely hard hit by the plague, for, as Horrox notes, nearly half the population of England died from the plague

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<sup>44</sup> Philip Ziegler, *The Black Death* (New York: Harper & Row, 1971), 43.

<sup>45</sup> Gottfried, *Black Death*, 50.

<sup>46</sup> *Ibid.*, 55.



within 18 months.

While the rate of infection and death varied from region to region, nearly all agree that East Anglia, the region of England surrounding Norwich, was the most severely afflicted region. It is possible that Norwich was infected with several strains of the plague: one arriving by means of sailing ships from the Netherlands and others arriving overland from London and Essex.<sup>47</sup> At the time of the first pandemic, Norwich's population was roughly 10,000 to 12,000. The plague arrived in Norwich in January of 1349, eventually took the pneumonic form, and remained until the Spring of 1350. It is estimated that half the beneficed clergy and 40 to 45 percent of the general population died in the first epidemic. Equally hard hit was the town of Bury St. Edmonds, and in its surrounding villages, mortality is estimated at 60 percent. As Gottfried notes:

It is likely that for all of East Anglia, plague mortality approached 50%, ranking it with Tuscany and parts of Scandinavia as the European areas most devastated by the Black Death.<sup>48</sup>

From England, the plague spread to Scotland, Ireland and Wales in 1349. Further, it continued its march across the European mainland, finally reaching Russia in 1350 or 1351. By the end of 1351, it had run its course. In 1351, agents for Pope Clement VI calculated the total number of dead at 23,840,000. This figure assumes a mortality rate of thirty percent: as Gottfried notes, "it is unerringly close to Froissart's claim that 'a third of

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<sup>47</sup> Ibid., 65.

<sup>48</sup> Ibid., 66

the world died,' a measurement probably drawn from St. John's figure of mortality from the plague in the Book of Revelations, a favorite medieval source of information."<sup>49</sup>

As a result of this great mortality, the European population experienced an initial decline. Many experts believe that it eventually began to recover. However, because the plague was to recur repeatedly for the next century, the population eventually became flat and showed few signs of recovery until at least 1460. Plague recurrences at the national and regional level were observed in England in 1361, 1369, 1379-83, 1389-93, 1400, 1405-07, 1413, 1420, 1427, 1433-34, 1438-39, 1457-58, 1463-64, 1467, 1471, 1479-80 and 1485.<sup>50</sup> While subsequent outbreaks do not appear to have been interpreted with the apocalyptic note that accompanied the first epidemic, the resulting climate of death in the wake of these repeated outbreaks is poignantly expressed in the macabre art, transi-tombs and literature of dying that so characterize the fifteenth century.<sup>51</sup> To further understand the social, religious and psychological implications of this "Great Mortality," let us now turn to a consideration of the short and long term effects of the plague.<sup>52</sup>

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<sup>49</sup> Ibid., 77.

<sup>50</sup> Jim Bolton, "'The World Upside Down': Plague as an Agent of Economic and Social Change," in *The Black Death in England*, 30.

<sup>51</sup> These tombs show with gruesome accuracy the decay of the body, including such details as the depiction of skeletal remains, mouse, snakes and snails preying upon the corpse or the stitches of the embalmers. See T. S. R. Boase, *Death in the Middle Ages*, 98-103.

<sup>52</sup> As Tuchman notes, the "Black Death" received this name only in later recurrences. It was known during the first epidemic as "The Pestilence" or "Great Mortality." See Tuchman, *Distant Mirror*, 101.

### Social, Psychological and Religious Effects of the Plague

Horrox, in introducing the primary texts she has compiled and translated on the Black Death, makes the following observation about the accounts of medieval chroniclers:

The very enormity of the disaster drove chroniclers to take refuge in clichés: there were not enough living to bury the dead; whole families died together; the priest was buried with the penitent he had confessed a few hours earlier; The same comments appear in chronicle after chronicle, and the result can seem curiously perfunctory, with only the occasional vivid detail bringing the reality of the situation before the reader. . . .<sup>53</sup>

Like Horrox, I also observed the repetition of such descriptions; however, rather than functioning as clichés, the descriptions seem to represent a repetition of the unthinkable, the attempts of survivors to assimilate fully the trauma they have experienced.

It is indeed clear from reading the chroniclers' accounts of the plague's devastation that they survived a situation of unspeakable horror. In our survey of the plague's effects, we shall begin by describing dimensions of the experience that were particularly difficult for survivors and then explore the religious response to the plague. Finally, we shall turn to the effects of repeated outbreaks and attempt to assess the long term consequences of the fourteenth century pandemic.

#### Social and Psychological Effects of the Plague

Undoubtedly, the most horrifying aspect of the experience of the plague was the massive amount of death it caused. Death on this scale had two consequences: first, *observers were overcome with the sheer number of dead and decaying bodies they encountered*. Boccaccio describes the situation in Florence.

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<sup>53</sup> Horrox, *Black Death*, 3.

As for the common people and the bourgeoisie . . . many dropped dead in the open streets, both by day and by night, whilst a great many others, though dying in their own houses, drew their neighbors' attention to the fact more by the mere smell of their rotting corpses than by any other means. And what with these, and the others who were dying all over the city, bodies were here, there and everywhere.<sup>54</sup>

Here is a comparable description from Vienna taken from the chronicle of the monastery of Neuberg in Southern Austria.

The contagious plague came in due course to Vienna and all its territories, and, as a result, countless people died and scarcely a third of the population remained alive. Because of the stench and horror of the corpses they were not allowed to be buried in churchyards, but as soon as life was extinct they had to be taken to a communal burial ground in God's Field outside the city, where in a short time five big deep pits were filled to the brim with bodies.<sup>55</sup>

Or again, from England from the chronicle of the cathedral priory of Rochester:

Alas, this mortality devoured such a multitude of both sexes that no one could be found to carry the bodies of the dead to burial, but men and women carried the bodies of their own little ones to church on their shoulders and threw them into mass graves, from which arose such a stink that it was barely possible for anyone to go past a churchyard.<sup>56</sup>

These accounts create the impression of a population overwhelmed with the sight and stench of death. Confrontation with death on this scale would have created a sense of revulsion. It is difficult to imagine what it would have been like for plague survivors to face such sights on a daily basis through the plague's extended course in a given region,

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<sup>54</sup> Giovanni Boccaccio, *The Decameron*, trans. G.H. McWilliam (Harmondsworth: Penguin Classics, 1972), in Horrox, *Black Death*, 32.

<sup>55</sup> "Continuation Novimontensis," ed. G. H. Pertz *Monumenta Germaniae Historica – scriptorum* IX, Hanover, 1851, in Horrox, *Black Death*, 59

<sup>56</sup> William Dene, *Anglia Sacra* (London: Henry Wharton, 1691) British Library, Cottonian MS, Faustina B V fos 96v-101, in Horrox, *Black Death*, 70.

and it is clear that over time, survivors simply became insensitive to the horror in order to survive. Boccaccio captures this growth of *apathy*:

[I]n fact, no more respect was accorded to dead people than would nowadays be shown towards dead goats. For it was quite apparent that the one thing which, in normal times, no wise man had ever learned to accept with patient resignation . . . had now been brought home to the feeble-minded as well, but the scale of the calamity caused them to regard it with indifference.<sup>57</sup>

A second consequence of the sheer volume of deaths accompanying the plague was *the collapse of normal customs for death and burial*. The account of Gilles li Muisis, Abbot of St. Giles at Tournai in Flanders, describes this effect.

Later, when the calamitous mortality was growing much worse, a proclamation was made on St. Matthew's Day [21 September] that nobody at all should wear black, or toll bells for the dead, that palls should not be placed over the bier, and that crowds should not be invited, as usual, to attend the funeral, but only two to pray for the dead and to attend the vigils and masses. The authorities had these things proclaimed, together with numerous other matters for the good of the city, under pain of certain penalties at the discretion of the *jures* and council.<sup>58</sup>

One reason for the adoption of this custom was the fact that the repeated tolling of the "passing bells" was filling the populace, men and women alike, with fear. However, it is also true that the magnitude of death simply made it impossible for clergy, physicians and society in general to respond in the customary ways to individual cases. The difficulty in obtaining clergy, in particular, led to a great deal of anxiety. This caused at least one Bishop, Ralph of Shrewsbury of Bath and Wells in England, to counsel priests to advise their parishioners that "if they are not able to obtain any priest [in time of illness] they should make confession of their sins (according to the teaching of an apostle) even to a

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<sup>57</sup> Boccaccio, *Decameron*, in Horrox, *Black Death*, 32-33.

<sup>58</sup> Gilles li Muisis from J-J. de Smet, ed., *Recueil des Chroniques de Flandre* II, Brussels, 1841, in Horrox, *Black Death*, 46.

layman, and if a man is not at hand, then to a woman.”<sup>59</sup> However, to avoid such extreme measures, the Bishop did provide a forty day indulgence to those who confessed to a priest before becoming ill. Further, penitents who confessed to lay ministers were exhorted, in the event of their recovery, to confess to a priest. Thus, tolerance for lay confessional ministry seemed clearly reserved for extremity.

Another painful effect of the plague occurs in a third consequence described repeatedly by chroniclers. Fear of contagion resulted in *abandonment of the dying and dead*. This effect was a result of terror, and it manifested the dehumanization wrought by the plague. The dying were not cherished, but were treated instead as objects to be avoided. This is most poignantly captured in Boccaccio’s description of the plague in Florence:

[In the wake of the plague] it was not merely a question of one citizen avoiding another, and of people almost invariably neglecting their neighbors and rarely or never visiting their relatives, addressing them only from a distance; this scourge had implanted so great a terror in the hearts of men and women that brothers abandoned brothers, uncles their nephews, sisters their brothers, and in many cases, wives deserted their husbands. But even worse, and almost incredible, was the fact that fathers and mothers refused to nurse and assist their own children as though they did not belong to them.<sup>60</sup>

and in de Mussis’ account of the plague in Piacenza.

And when the sick were in the throes of death, they still called out piteously to their family and neighbors, ‘Come here. I’m thirsty, bring me a drink of water. I’m still alive. Don’t be frightened. Perhaps I won’t die. Please hold me tight, hug my wasted body. You ought to be

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<sup>59</sup> Bishop Ralph of Bath and Wells, cited in Francis.A. Gasquet, *The Black Death of 1348 and 1349*, 2<sup>nd</sup> ed. (London: Bell & Sons, 1908), 94.

<sup>60</sup> Boccaccio, *Decameron*, in Horrox, *Black Death*, 30.

holding me in your arms.<sup>61</sup>

De Mussis goes on to ask, "What a tragic and wretched sight! Who would not shed sympathetic tears? . . . But our hearts have grown hard now that we have no future to look forward to."<sup>62</sup>

Fear of contagion led, in some places, to isolating of the sick, ejecting them from towns and, in draconian style in Milan, to the walling up of the occupants of the first three homes containing the plague, where all the inhabitants, dead or alive, were left to perish.<sup>63</sup> But, as Horrox notes, the best safeguard was flight -- as advocated in a German manuscript, "Clever doctors have three golden rules to keep us safe from pestilence: get out quickly, go a long way and don't be in a hurry to come back."<sup>64</sup> Flight was the preferred strategy of the rich, but those who fled were not always at ease with the solution, in part, because they understood that God's anger, in the form of the plague, could follow them anywhere. Clearly, those who were well harbored ambivalence and guilt about abandoning the sick, factors which may only have contributed to their burden of grief. The frequency with which flight was adopted, even by the clergy, underscores the human instinct for survival at the same time as it highlights the disruption of the fabric of community that invariably accompanies disaster.<sup>65</sup>

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<sup>61</sup> Gabriele de Mussis, *Historia de Morbo*, in Horrox, *Black Death*, 22.

<sup>62</sup> *Ibid.*, 23

<sup>63</sup> Ziegler, *Black Death*, 54.

<sup>64</sup> Horrox, *Black Death*, 108.

<sup>65</sup> The sense of "loss of community" is one of the most significant effects observed in twentieth century accounts of multiple loss. See, for example, Kai T. Erikson's account of this phenomenon in the Buffalo Creek Disaster in his chapter entitled, "Collective Trauma: Loss of Communitality" in his book,

A fourth effect of the plague was *ambivalence among the worried well*. How were they to live while the plague raged? As we have already noted, some chose to flee and, in their flight, to create a peaceable existence with good food, fine wine and pleasant conversation. Others, perhaps more surely anticipating death, chose to “drink heavily, enjoy life to the full, go round singing and merrymaking, gratify all of one’s craving whenever the opportunity offered and shrug the whole thing off as one enormous joke.”<sup>66</sup> Then, of course, others steered a middle course between complete denial and total abandon. According to Boccaccio, these did not restrict their diet as much as the cautious, nor indulge as freely as the reckless. Instead, they moved about freely with flowers or other aromatic substances in their hand to protect themselves from the stench of the sick and dead. Since there was no clear consensus either about the cause of the plague or its treatment, it was anyone’s guess as to which strategy would ultimately prove most effective.

One final, troubling effect of the plague was to prove particularly damaging to society, namely, *suspicion of outsiders*. This effect was to lead ultimately to the death of thousands through persecution. Evidence for this fear occurs in several accounts, such as one from Padua.

A single stranger carried the infection to Padua, to such effect that perhaps

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*Everything in Its Path: Destruction of Community in the Buffalo Creek Flood* (New York: Simon & Schuster, 1976), 186-245.

<sup>66</sup> Boccaccio, *Decameron*, in Horrox, *Black Death*, 29.



a third of the people died within the region as a whole. In the hope of avoiding such a plague, cities banned the entry of all outsiders with the result that merchants were unable to travel from city to city.<sup>67</sup>

A comparable account may be found in the autobiography of the fourteenth century German mystic, Henry Suso, who describes how his traveling companion was accused of poisoning wells when he traveled to a strange village. The unfortunate man was seized and imprisoned and he was only released when Suso paid a stiff fine on his behalf. In the end, Suso himself was accused of being a poisoner, and he was only able to escape this danger with the help of a priest who overheard his desperate prayers for deliverance. The priest took him in and kept him overnight and helped him make his way safely out of the town in the morning.<sup>68</sup> This tendency to blame strangers and foreigners for inexplicable misfortune points to a nearly universal psychological phenomenon, as the continued existence of scapegoating in times of tragedy attests.

Clearly, the advent of the plague resulted in many difficult emotions for those unfortunate enough to experience the suffering and death it wrought. Contemporary accounts attest to the following range of feelings: helplessness, numbness, shock, apathy, denial, guilt, relief for survival, gratitude for life, a loss of certainty, a sense of hopelessness, vulnerability, pessimism, an inability to assimilate the extent of disaster, an awareness of the irony of life, a sense of life as precarious, a loss of direction, and an awareness of paradox. Living with this full panoply of emotions was certainly unsettling.

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<sup>67</sup> Cortusii Patavina Duo, sive Gulielmi et Abrijeti Contusiorum Historia de Novitatibus Paduae et Lombardiae ab anno MCCLVI usque as MCCCLXIV, in L. A. Muratori, ed., *Rerum Italicarum Scriptores* XII, Milan, 1728 in Horrox, *Black Death*, 34-35.

<sup>68</sup> Horrox, *Black Death*, 224-26.

Perhaps the most unsettling experience of all, however, was attempting to understand why: why had this suffering come to afflict the population? While several scientific explanations were advanced, the most common and compelling belief was that the plague resulted from the action of the Divine.<sup>69</sup> Let us turn, therefore, to an exploration of the religious explanations for the plague and to their pastoral implications for the faithful.

#### Religious Explanations for the Plague and Their Effect on the Faithful

Perhaps the most common and most troubling explanation for the plague was theological: the plague was understood as a form of divine vengeance for human sinfulness. In a time when scientific and medical knowledge seemed grossly inadequate in the face of human pain, it is perhaps understandable that religious explanations would be invoked.

One of the most sustained theological accounts for the plague is found in Gabriele de Mussis' *Historia de Morbo*.<sup>70</sup> His account of the plague's arrival in Italy is the most frequently cited; as Horrox notes, what is less well known is that it occurs in the

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<sup>69</sup> Besides the dominant religious explanation, contemporary accounts provide a number of scientific explanations for the plague. These include the famous astrological explanation offered by the faculty of the University of Paris that attributed the plague to the 1345 conjunction of Mars, Saturn and Jupiter. More sophisticated explanations attempted to wed this astrological phenomena with the belief in humors to explain why some grew ill and others did not. Other scientific explanations implicated a corruption in the air that was, at times, attributed to the release of foul vapors from earthquakes that preceded the plague. The popularity of this explanation explains why fourteenth century art shows doctors ministering to plague victims with pomanders before their faces to protect them from foul odors. It was also known that the plague could be contracted through contact with the dying and their possessions, although the exact means of infection was obviously unknown. In addition, some thought that worry or brooding on the plague could bring on its symptoms. Finally, the explanation that has been most ridiculed, but one that made sense given the theories of vision prevalent in the day, was the belief that the plague could be contracted through sight, through looking at those who were infected. For a survey of these interesting pseudo-scientific explanations, see Horrox, *Black Death*, 158-206.

<sup>70</sup> Horrox, *Black Death*, 14-26.

context of an extended meditation on the plague as an expression of divine anger. De

Mussis' account begins as follows.

May this stand as a perpetual reminder to everyone, now living and yet to be born, how almighty God, king of heaven, lord of the living and of the dead, who holds all things in his hand, looked down from heaven and saw the entire human race wallowing in the mire of manifold wickedness, enmeshed in wrongdoing, pursuing numberless vices, drowning in a sea of depravity because of a limitless capacity for evil, bereft of all goodness, not fearing the judgments of God, and chasing after everything evil, regardless of how hateful and loathsome it was. Seeing such things he called out to the earth: 'What are you doing, held captive by gangs of worthless men, soiled with the filth of sinners? Are you totally helpless? What are you doing? Why do you not demand human blood in vengeance for this wrongdoing? Why do you tolerate my enemies and adversaries? When confronted by such wantonness, you should have swallowed my opponents. Make yourself ready to exercise the vengeance which lies within your power.'<sup>71</sup>

De Mussis describes an extended dialogue between God and creation in which God pronounces the following judgment on humankind.

I pronounce these judgments: may your joys be turned to mourning, your prosperity be shaken by adversity, the course of your life be passed in never-ending terror. Behold the image of death. Behold, I open the infernal floodgates. Let hunger strike down those it seizes, let peace be driven from the ends of the earth; let dissensions arise; let kingdoms be consumed in detestable war; let mercy perish throughout the world; let disasters, plagues, violence, robberies, strife and all kinds of wickedness arise. Next, at my command, let the planets poison the air and corrupt the whole earth; let there be universal grief and lamentation. Let the sharp arrows of sudden death have dominion throughout the world. Let not one be spared, either for their sex or their age; let the innocent perish with the guilty and no one escape.<sup>72</sup>

This diatribe continues with a condemnation of the clergy and ends with a description of God's vengeance unleashed on the earth.

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<sup>71</sup> De Mussis, *Historia de Morbo*, in Horrox, *Black Death*, 14.

<sup>72</sup> *Ibid.*, 15. Note how de Mussis' description of God's judgment captures the principal failings of the fourteenth century that we have already observed.

After this warning had been given to mortals, disease was sent forth; the quivering spear of the Almighty was aimed everywhere and infected the whole human race with its pitiless wounds.<sup>73</sup>

Thus, in de Mussis' view, the plague is a form of divine punishment sent directly from God's hands to afflict the innocent and guilty alike.

In his article on the iconography of the plague in the late Middle Ages, John Friedman provides a disturbing pictorial representation of this figure of divine vengeance drawn from fifteenth century German woodcut illustrating a plague leaflet.



Vengeful God with Arrows<sup>74</sup>

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<sup>73</sup> Ibid., 16.

<sup>74</sup> John B. Friedman, "He hath a thousand slayn this pestilence': The Iconography of the Plague in the Late Middle Ages," in *Social Unrest in the Late Middle Ages*, ed. Francis X. Newman (Binghampton, N.Y.: Medieval and Renaissance Texts and Studies, 1986), 102. The icon of a vengeful God with arrows, *pestblatt*, German, 15<sup>th</sup> century, is after Paul Heitz and W. L. Schreiber, *Pestblätter des XV Jahrhunderts* (Strassbourg, 1901), 3.

This account of the plague's origins thus conceives of the plague as a reversal of creation and may explain the common Scriptural allusions to Noah that occurred at the time of the Black Death. The plague was understood as an "undoing" of the goodness of the world, because of human sin, in the same manner as the flood in Genesis.

Of course, de Mussis, an attorney, was undoubtedly trained as a rhetorician rather than as a theologian. This background may partially account for his stark portrayal of God's anger. Nevertheless, even the theologians of the day turned to divine anger as an explanation for the plague, although their rhetoric was softened a bit and tends to portray a kind and merciful God who can be moved through the repentance of the faithful.<sup>75</sup>

What sins were understood to be the occasion for the unleashing of such terrible wrath? Several catalogues of sin are cited, but the sins most commonly mentioned include the seven deadly sins: pride, avarice, envy, lust, anger, sloth, and gluttony. Other sins invoked as explanations include the lack of good faith and equity among judges, the pettifogging of lawyers, the hypocrisy of religious, and the vanity of ladies. Critics also condemn the failure of those in leadership, including the unjust favoritism of kings and the greed of clergy and prelates. But, perhaps the most commonly cited causes for God's disfavor include the divine disapproval of tournaments and the scandalous styles of the times. The moralists criticized the tournaments for their frivolity and excess and the fashions for their indecency which incited the faithful to

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<sup>75</sup> This accounts for the allusions to the story of Jonah that occur, for example, in the pastoral letter of Ralph of Shrewsbury, Bishop of Bath and Wells, in which he calls upon the faithful to confess their sins, recite psalms and perform works of mercy so that they may be rescued from destruction as the people of Ninevah were in the days of the prophet. See Horrox, *Black Death*, 112-13.

vanity and immorality.<sup>76</sup> Finally, in the fourteenth century as in the twentieth, the failure of youth and adolescents to obey their elders is noted as one cause of misfortune, in the face of which parents are exhorted to discipline, in this case by Reason in *Piers the Plowman*.

And then he charged chapmen to chastize their children  
'Don't let wealth spoil them while they are young  
Nor for fear of the pestilence indulge them beyond reason.  
My mother and father both told me  
That the dearer the child the more teaching it needs.  
And Solomon said the same, in his book of Wisdom:  
*Qui parcit virge odit filium,*  
Which is in English, if you want to know:  
Who spares the rod spoils the child.'<sup>77</sup>

Clearly, the dominant religious explanation was not without its flaws. Since the days of the Psalmists, if not before, astute observers have noted that the innocent as well as the wicked suffer in this age. How, then, did religious commentators writing in the days of the plague explain this troubling aspect of theodicy?

Usually, they resorted to a second understanding, namely, the view that "plague is a spiritual blessing and a sign of God's mercy, since it prompts men to repent in this life and be spared the pain of hell in the next."<sup>78</sup> This view was articulated by Thomas Brinton, one of the most famous preachers in England in the fourteenth century. Of course, this understanding might explain the dynamics that led to one's survival, but it did

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<sup>76</sup> For sins associated with tournaments, see Henry Knighton's account in Horrox, *Black Death*, 130. For a critique of fashion, see especially the chronicle of John of Reading in Horrox, 131-34.

<sup>77</sup> William Langland, *Piers the Plowman*, in Horrox, *Black Death*, 136.

<sup>78</sup> Horrox, *Black Death*, 98.

not explain the deaths of innocents. These Brinton attributed to the sins of others, for he believed, for example, that the deaths of innocent children were due to the sins of their parents. He viewed these deaths as

a release from prison, an end of exile and toil, an escape from all danger,  
a breaking of chains, a return to the homeland, a going forth to glory.<sup>79</sup>

The death of innocent children, therefore, provided just one example of the way in which God sometimes punished the innocent to chastise sinners, “the most evil and guilty.”<sup>80</sup>

A final theological explanation advanced for the 1348-49 outbreak of the plague was the view that it heralded the end of the world. Of course, this explanation lost force in repeated epidemics, nevertheless, in the first and most damaging outbreak, the invocation of apocalyptic imagery and explanation seemed both appropriate and compelling.

#### Pastoral Responses to the Plague

Clearly, people faced with the plague turned to religious explanations and in this, “all roads led to Rome.” Whether one understood the plague as a punishment for sin, a wake up call or a harbinger of the end times, the appropriate response was the same: the faithful must repent and be saved. Therefore, a variety of vehicles were developed toward this end.

One of the most common religious resources mustered against the plague was processions. The use of processions as a weapon against the plague had a venerable history, as Gregory the Great had led a procession through Rome in 590 during

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<sup>79</sup> Ibid., 146.

<sup>80</sup> Ibid.

Justinian's Plague. Gregory had chanted the great litany composed for the occasion. As the procession made its way through the streets of the city, Michael the Archangel appeared on top of the mausoleum of Hadrian sheathing his sword. This was interpreted as a sign that God had been appeased, and it led to the christening of the mausoleum as Castel Sant'Angelo. To commemorate the occasion, a great statue of the archangel was placed atop the building.<sup>81</sup> When the plague returned in the Middle Ages, the Pope and Bishops organized processions as a first line of resistance. As Tuchman notes, some of these penitential processions lasted three days and were attended by as many as 2,000 people. Unfortunately, they also encouraged the spread of the infection, and when this became clear, Pope Clement VI finally prohibited them.<sup>82</sup>

Other pious activities encouraged in the face of the plague included the recitation of psalms, pilgrimage, the embracing of acts of penance and attendance at Mass. Brinton's program for repentance included confessing one's sins, praying for other believers, serving God, adopting a habit of watchfulness and meditating on the Passion of Christ.<sup>83</sup>

Medieval art and documents testify to the importance of intercession as an aid in the plague. Three saints, in particular, were considered as powerful protectors. The first was the Blessed Virgin Mary. In his survey of late medieval iconography developed in response to the plague, Friedman provides an image of the Virgin and plague victims

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<sup>81</sup> Ibid., 95

<sup>82</sup> Tuchman, *Distant Mirror*, 99-100.

<sup>83</sup> Horrox, *Black Death*, 147-48.



taken from a German altarpiece. In this image, the Virgin extends her mantle over plague victims to ward off the arrows of God's wrath.<sup>84</sup> This realistic depiction places arrows in the spots where plague victims normally experienced buboes.



Virgin and Plague victims, Altarpiece, church of the Carmelites, Göttingen, Hanover, Niedersächsische Landesgalerie, 1424.  
*Courtesy of Niedersächsische Landesgalerie.*

Friedman also cites two popular prayers to the Virgin for protection against the plague, both works of John Lydgate. In one poem, he asks the Virgin to "Pray/ Thy swete son.../That no perylous plage of pestilence.../Entyr in England." In the second, he begs her:

do not now disdeyne  
Contraryous planetis to Appeese & Represse,  
Whos dredefull werrys do men full Mortall peyne,  
Be vnwholesome Eyres Cawsyng greete syknesse.<sup>85</sup>

<sup>84</sup> Friedman, "Iconography of the Plague in the Late Middle Ages," 85, 104.

<sup>85</sup> *Ibid.*, 85.

Devotion to two other patrons grew at this same time. St. Sebastian became particularly popular because of an association between this saint and arrows. Sebastian was the patron of archers and crossbowman. According to legend, he was a member of the imperial guard martyred by the emperor, Diocletian, in the third century. He was shot with arrows and assumed dead, but he recovered through the ministrations of Irene, the widow of another Christian martyr. When the emperor discovered this, he had Sebastian bludgeoned to death. The image of being shot with arrows was a popular device for describing the onslaught of the plague, and the saint's body, pierced by arrows, yet alive, became a potent symbol for plague victims.<sup>86</sup> As a result, his relics in Flanders and Italy drew many pilgrims, and Friedman provides a number of representations of Sebastian interceding on behalf of those afflicted with the plague.

A second, popular patron was St. Roche. Unlike Sebastian, Roche actually contracted the plague, yet survived. In 1379, while on a pilgrimage during which he cured plague victims, he was falsely imprisoned as a spy near Montpellier where he eventually died. Friedman notes that both Sebastian and Roche appear on plague coins and tokens designed to avert the disease. Further, many pious confraternities took the names of these saints and developed images of them in wood sculpture, wall painting and stained glass. Confraternities were composed of pious lay persons who banded together to arrange for masses for their souls after death and for prayer protection from the plague in life, and they were another common religious reaction to the dangers of the plague.<sup>87</sup>

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<sup>86</sup> Horrox, *Black Death*, 97.

<sup>87</sup> Friedman, "Iconography of the Plague in the Late Middle Ages," 85-88.

Besides these pious practices designed to avert the plague, Europeans also resorted to extreme measures against fellow sufferers in the name of God. Two of the most disturbing and related chapters in the fourteenth century history of the Black Death treat of the penitential practices of the flagellants and the associated persecution of the Jews. Let us now turn to an examination of these phenomena, for they also shed light on the religious response to the plague.

#### Extreme Religious Reactions: Persecution and Flagellation

In his introduction to the Jewish persecutions accompanying outbreaks of the plague, Ziegler attempts to explain the rationale and tactics accompanying this horrible practice. Persecution in the Middle Ages began with the sense of helplessness people felt in the face of the plague's suffering. Rather than enduring the paralysis that comes with such helplessness, people, seeking explanation and relief, often attempted to find solace in action. In the absence of satisfying medical explanations, the population sought a scapegoat: someone near at hand who could be blamed for the present suffering. As Ziegler notes:

Few doubted that the Black Death was God's will but, by a curious quirk of reasoning, medieval man also concluded that His instruments were to be found on earth and that, if only they could be identified, it was legitimate to destroy them. What was needed, therefore, was a suitable target for the indignation of the people, preferably a minority group, easily identifiable, already unpopular, widely scattered and lacking any powerful protector.<sup>88</sup>

Strangers and outsiders were among those targeted for persecution and violence in the course of the plague's advance. Ziegler describes the ways in which the category,

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<sup>88</sup> Ziegler, *Black Death*, 97.

“stranger,” was nuanced depending on circumstances. In Spain, Arabs were suspect, while throughout Europe, pilgrims were viewed with suspicion. In Narbonne, the English were targeted. The second most widely feared group were the lepers. Already, in Languedoc in 1321, lepers were burnt on the suspicion of poisoning wells, yet even in this situation, it was assumed that they were complicit with Jews.<sup>89</sup>

A number of factors combined to isolate the Jews as the preferred target of persecution. As Tuchman notes, Jews were eternal strangers, separated by choice from the Christian world, hated by Christians for centuries for their alleged role in Christ’s death, and suspected of harboring ill will toward their Christian neighbors.<sup>90</sup> Their profession, besides their differing religious beliefs, provided a further inducement for violence against them. In the Middle Ages, the Jews served as moneylenders, because Christians were forbidden from using money to make money. Over time, as the banking industry developed, the Jews experienced increasing marginalization as lenders, until in many places, they functioned more as petty lenders and pawnbrokers. But the exorbitant interest they charged, related to their need to bribe public officials to sustain their businesses, made them unpopular and easy targets for hatred.<sup>91</sup>

The roots of violence against them may be traced to a tradition of anti-Semitism in Christian theology. This was reflected in canon law and in the writings and

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<sup>89</sup> Ibid, 97-98.

<sup>90</sup> Tuchman, *Distant Mirror*, 109.

<sup>91</sup> Ziegler, *Black Death*, 98.

preaching of such respected theologians as John Chrysostom, Augustine and Thomas Aquinas. The latter, in fact, concluded that “since Jews are the slave of the Church, she can dispose of their possessions.”<sup>92</sup> This intellectual climate of intolerance led inevitably to persecution and violence. During the Crusades, massacres of Jewish communities accompanied the Crusaders march to Palestine as the cry, “HEP, HEP” for *Hierosolyma est Perdita* (Jerusalem is lost) became the battle cry against them. The violence seemed justified, since Christians blamed Jews for the capture of the Holy Sepulcher by the Moslems. With the arrival of the Inquisition in the thirteenth century, the Jews were faced both with charges of ritual murder and the wearing of badges.<sup>93</sup> The existence of the Jew in Medieval Europe was precarious, indeed, and Jews were dependent on the favor of kings and rulers to maintain their tenuous toehold on property and possessions.

In the event of the plague, the charge leveled against Jews was the poisoning of wells “with intent to kill and destroy the whole of Christendom and have lordship over all the world.”<sup>94</sup> The first persecutions occurred in Southern France in the Spring of 1348. In May of 1348, there was a massacre in Provence and widespread extermination of the Jews in Narbonne and Carcassone. The movement against the Jews gained particular momentum, however, following the extraction under torture of a confession of guilt in Chillon, in Savoy in September, 1348. Following the circulation of this confession, violence seemingly erupted with unspeakable brutality throughout central Europe. Jews

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<sup>92</sup> Tuchman, *Distant Mirror*, 110.

<sup>93</sup> *Ibid.*, 110-13.

<sup>94</sup> Chronicle of Gilles li Musis, cited in Tuchman, *Distant Mirror*, 109.

were banned from the city of Zurich for all time on September 21, 1348. In Basle, all the Jews were penned up in a building and burned alive. In November of 1348, the Jews were burned at Solothurn, Zofigen and Stuttgart; in December at Landsberg, Burren, Memmingen and Lindau; and in January at Friburg, Ulm and Speyer. In February, Jews were massacred at Gotha, Eisenach and Dresden and 2,000 Jews were murdered in Strassbourg; while in March, Jews were killed at Worms, Baden and Erfurt. For a time, the violence ceased, but its return in the summer of 1349 resulted from the influence of the Flagellants.

The Flagellants were extreme penitential groups in Europe that arose in conjunction with the plague and were particularly evident in Germany, France and the Low Countries. These groups practiced public self-scourging, the aim of which was to avert God's anger against sinners. The movement had its roots in Italian monastic communities in the eleventh century, but the practice of group flagellation underwent a metamorphosis, re-emerging at the height of the plague with a strong public focus. The Flagellants would march into a town in a long procession, two by two. Sometimes there were thousands of members, at other times, hundreds. They wore distinctive clothing marked with red crosses and segregated themselves by sex. Upon entering the town, they would process to the church, accompanied by the ringing of church bells. The Flagellants chanted special litanies and sang the *Stabat Mater* and other hymns devised to accompany their rites. The central focus of their activity, usually conducted in the public square, was thrashing by the group's Master for particular sins. This was followed by self-flagellation with scourges fashioned from sticks with knotted tails from which protruded needle-like spikes. The Flagellants proceeded to whip themselves with these instruments until they

drew blood. These rituals were accompanied by public hysteria, with spectators crying, sobbing, howling and tearing at their hair and body in reaction to the excesses they witnessed.

At first, Ziegler notes, the movement was well-regulated and disciplined. New entrants had to obtain permission of their spouse, confess their sins, show that they were able to support themselves and vow obedience to their Master. Over time, however, the group's arrogance grew and this led to conflict with the Church. Conflict was rooted in the group's repudiation of Church authority, their ridicule of the Eucharist and their refusal to reverence the host. Eventually, their actions became more extreme and they were known to interrupt church services, drive clergy from their churches and loot church property. As the group became more and more revolutionary, it also became more violent, and unfortunately, the Flagellants directed their violence against the Jews. As Tuchman notes, "In every town they entered, the flagellants rushed for the Jewish quarters, trailed by citizens howling for revenge upon the 'poisoners of the wells.'"<sup>95</sup> Their actions led to the massacre of Jews in Frieburg, Augsburg, Nurnberg, Munich, Konigsberg, Regensburg, Worms, Frankfurt, Cologne and Mainz. Horrified by these massacres, the Church and civil authorities took action to suppress the movement. On October 20, 1348, Clement VI issued a papal bull denouncing the flagellants for contempt of church discipline and ordering prelates to suppress their pilgrimages. Further, the University of Paris denied their claim of divine inspiration. Suddenly, in the words of the

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<sup>95</sup> Tuchman, *Distant Mirror*, 115.

Chronicler Henry of Herford, the flagellants vanished “as suddenly as they had come, like night phantoms or mocking ghosts.”<sup>96</sup>

While they flourished, however, they did irreversible damage to the Jewish population and their sympathizers.<sup>97</sup> By 1351, the persecution of the Jews was over, but the loss of 60 large and 150 smaller Jewish communities considerably weakened the Jewish presence in Europe. In all, Jews experienced some three hundred and fifty massacres during the plague years.<sup>98</sup> This legacy of suffering remains as a painful reminder of the human need for vengeance in the face of massive and inexplicable pain and suffering. That such vengeance is too often wrought in the name of God makes it all the more disturbing.

#### The Longer Term Psychological, Religious and Pastoral Effects of the Plague

In attempting to assess the repercussions of the plague, Rosemary Horrox notes that late nineteenth century historians had given the plague a “starring role” in the drama of change. The plague was viewed, for a time, as an agent of cataclysmic change in a number of domains, including art, religion, social arrangements and the economy. Over time, however, historians have moderated this view somewhat. As Horrox notes, historians are less likely to attribute change to a single cause. Instead,

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<sup>96</sup> Ibid., 116.

<sup>97</sup> As Ziegler notes, a number of European rulers did attempt to protect their Jewish subjects. The town councilors of Cologne urged their colleagues at Strasbourg to deal with the Jews more moderately, although their efforts were unsuccessful. Casimir of Poland, under the influence of his Jewish mistress, Esther, was able to prevent persecution there. Finally, Pedro IV of Aragon intervened on behalf of Jews whose homes had been attacked by the residents of Barcelona. He also intervened on behalf of several leading Jews in Tarragona who had been ruined by the loss of their homes and documents. When the plague returned in 1361, the Jews appealed to him for protection and he set an armed guard at the gates of the ghetto. See Ziegler, *Black Death*, 106-08.

<sup>98</sup> Ibid., 109.



Change is more likely to be seen as the result of a complex interplay of forces, of which the plague is still only one; albeit a more powerful one than has lately been allowed.<sup>99</sup>

In attempting to assess religious changes in the wake of the plague, it is wise to attend to these words. It is clear that the plague had a significant effect in a number of aspects of religious life, such as the composition of the clergy, their status and educational level, and a growing restiveness in the face of traditional theologies. However, in assessing the effects of the plague on the religious life of the late fourteenth century, we must not overlook the importance of equally significant factors, such as the papal schism, which had far-reaching implications for the institution of the Church and piety of the faithful. As Harper-Bill notes in accounting for the rise of Wycliff and his followers:

The vicissitudes of papal history, just as much as the ravages of plague, must be taken into account when considering the history of the English Church and of religion in England in the fourteenth and early fifteenth centuries. It is surely significant that the first notable outbreak of heresy in England coincided with the onset of the Great Schism, and that religious dissent in England evaporated rapidly once unity was restored in the church.<sup>100</sup>

In considering the longer term effects of the plague, we shall examine three areas: mindset, morality and mood.

Ziegler offers a very cogent analysis of the mindset of the faithful. In his view, medieval people undoubtedly felt let down by the Church. While the faithful were willing to accept that the plague was the work of God and a response to sin, they found it

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<sup>99</sup> Horrox, *Black Death*, 236.

<sup>100</sup> Christopher Harper-Bill, "The English Church and English Religion after the Black Death" in *Black Death in England*, ed. Ormrod and Lindley, 83.

difficult to understand why the Church had not been able to warn them earlier that the patience of God was being tried to such an extreme degree. When suffering came, people were disillusioned with the Church for failing to issue more timely and effective warnings.<sup>101</sup>

Clearly, there must have been a gap between people's expectations of the Church and the Church's ability to respond to them. The reality of the schism and the rhetoric of sin in the time of the plague undermined the authority of the institution, for each of these factors highlighted discrepancies between ideals and reality. The rhetoric of sin seemed inadequate when the innocent appeared to die at as great a rate as sinners in the plague. Further, the schism highlighted the Church's greater concern with temporal than spiritual matters. Each of these factors strained credulity. The disappointment that accompanied them was at least partly responsible for the pessimism of the late fourteenth and early fifteenth century that is everywhere expressed in its art and literature.

Contemporary observers could not have failed to note that "God's wrath seemed just as hot against the Church as against people," for clergy died in even greater numbers than laity.<sup>102</sup> In Ziegler's opinion, this fact along with clerical abuses, such as abandonment of the sick and dying during the plague and clerical greed and laziness after the plague, must surely have exposed the vulnerability of the clergy and been a factor in their decreased popularity.<sup>103</sup> The fact that they represented a God increasingly portrayed as wrathful and

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<sup>101</sup> Ziegler, *Black Death*, 260.

<sup>102</sup> *Ibid.*, 260.

<sup>103</sup> These aspects of clergy behavior are noted by a number of observers. See, for example, Horrox, *Black Death*, 241-42, 310-12

retributive could not have helped their popularity, either. Nor would it be helped by the fact that clergy fitness and education were depressed after the plague in comparison to pre-plague standards. At a time when the Church faced terribly perplexing pastoral problems, the average priest was increasingly ill-equipped to respond.

A second, significant effect was the increasingly lax morality of the populace.

According to the chronicler, Jean de Venette:

men were more greedy and quarrelsome; women became sexually degenerate; clergy haunted taverns and gambling dens; [and] little men bustled about to make themselves the equals of their betters.<sup>104</sup>

On the one hand, many accounts of post-plague life describe decreased morality and, as Ziegler suggests, it may perhaps be attributable to “relief from almost intolerable tension and the enjoyment of more money than one is used to having,” since one notable effect of the plague was a marked increase in wages.<sup>105</sup> On the other hand, when the fabric of community unravels as it must have in the aftermath of the Black Death, both loss of morale and of community consensus may also explain the marked impact on morality.

Finally, the plague affected the mood of the populace. In the wake of the Black Death, all commentators agree that the psychological climate was marked by a pervasive pessimism, a “neurotic and all-pervading gloom.”<sup>106</sup> This gloom was evident in the moralistic tone of the literature of the day, such as Langland’s *Piers Plowman*, and in the

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<sup>104</sup> Horrox, *Black Death*, 242.

<sup>105</sup> Ziegler, *Black Death*, 272.

<sup>106</sup> *Ibid.*, 274.

obsessive fascination with death that characterized the art and literature of the fifteenth century, with its “Dance of Death” theme. As Horrox rightly notes, most survivors lived with an increased sense of guilt and vulnerability that came with the knowledge that

their new prosperity was, in effect, being paid for by crisis mortality; or to put it in more personal terms, that the increased expectations of the survivors derived ultimately from the deaths of family and friends.<sup>107</sup>

This sense of vulnerability was reflected in increased emphases on the unpredictability of death and on the corruptibility of the body. A further phenomenon directly related to the plague was the awareness that even seemingly healthy people might be struck down without warning. As Horrox notes, “the association of plague with unprepared death was one of its particular terrors.”<sup>108</sup> As twentieth century research with survivors makes clear, exposure to death on both the grand and disturbing scale associated with the plague leaves an indelible imprint on the memory and psyche of survivors, one which continues to exert powerful effects for years after the initial trauma.

As a plague survivor herself, Julian was not exempt from these dynamics. Let us turn, therefore, to an examination of her revelations and her theological reflection upon them to explore in what ways they may have exerted their effects.

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<sup>107</sup> Horrox, *Black Death*, 244.

<sup>108</sup> *Ibid.*, 245.

## CHAPTER 6

### “I KEEP THEE FULL SURELY”: JULIAN’S TRIUMPH OVER DEATH<sup>1</sup>

For individual hibakusha [Hiroshima survivors] the experience of being loved and cared for could, gradually and against obstacles, re-create life affirming imagery and re-establish the capacity to live.<sup>2</sup>

The reason we are greatly troubled by [our pains] is our ignorance of love...For some of us believe that God is all-mighty and may do everything, again that he is all-wisdom and can do everything, but that he is all-love and will do everything, there we hold back. And this ignorance, that is what most hampers God’s lovers in my eyes. . . .or of all the properties of the blissful Trinity, it is God’s will that we be most sure of and take most delight in his love; for love makes us strong. . . .<sup>3</sup>

The fourteenth century was a time of massive death and painful suffering. Julian, born almost mid-way through the century and living in one of England’s greatest cities, would have known this suffering personally. She was exposed to several epidemics of the second plague pandemic. Further, she would have been touched by the effects of war and the disillusionment and dissent that marked the religious culture of her day.

Undoubtedly, certain parallels between Julian’s time and the present century, including the presence of destructive wars, senseless violence and costly pandemics, have helped to fuel the scholarly interest in Julian’s work that began in the early part of this

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<sup>1</sup> This quotation is drawn from Anna Maria Reynolds’ translation of the short text, *A Shewing of God’s Love*, chap. 17, 50, and represents Christ’s assurance to Julian that she will not be overcome by her sin.

<sup>2</sup> Lifton, *Death in Life*, 253.

<sup>3</sup> Julian of Norwich, *Revelation of Love*, chap. 73, 169.

century with the publication of Grace Warrack's translation of Julian's text.<sup>4</sup> Many of the popular titles devoted to Julian and her theology play on these parallels. These include, for example, Robert Llewellyn's edited volume, *Julian, Woman of Our Day*, and Sheila Upjohn's, *Why Julian Now? A Voyage of Discovery*.<sup>5</sup> Many contemporary seekers, intrigued by these parallels, seem drawn to Julian's theology in an attempt to find answers to age-old questions about sin, suffering, love and hope that have arisen in each period.

As I have already suggested, my own journey with Julian was sparked by a similar search. In reading Julian's text, I heard echoes, echoes of a witness to suffering and death offered from the perspective of a survivor. I was intrigued first, by the fact of the echoes and second, by the hope and vitality that characterized the spirituality of this brave witness.

In light of this fact, the purpose of the present chapter is to develop and support my thesis that Julian may be understood as a survivor of plague-related multiple loss. In developing my argument, I am seeking to flesh out the echoes I heard in the text. This process will involve several steps. First, we shall consider several assumptions about the effect of the plague on Julian that have influenced the understanding of her life and work. Second, we shall consider Robert Jay Lifton's psychology of the survivor, since it provides a helpful analytical tool for exploring the effects of plague loss on Julian. Third,

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<sup>4</sup> Julian of Norwich, *Revelations of Divine Love*, trans. Grace Warrack (London: Methuen, 1907).

<sup>5</sup> Robert Llewellyn, ed., *Julian, Woman of Our Day* (London: Darton, Longman & Todd, 1985); and Sheila Upjohn, *Why Julian Now?: A Voyage of Discovery* (Grand Rapids: W. B. Eerdmans, 1997).

after describing his theory, we shall apply it to Julian's text to see how it might illuminate an understanding of her experience and theology.

The fourth part of our analysis is hermeneutic. Following David Tracy, we shall ask what manner of being-in-the-world emerges from Julian's theology for survivors of plague-related multiple loss. That is, we shall attempt to illustrate through Julian's eyes what made it possible to live as if "all shall be well, all shall be well and all manner of things shall be well." Following this analysis of her theology, we shall then explore Julian's distinctive spirituality: a spirituality of trust and longing. In a later chapter, we shall draw further on this analysis as we explore the implications of her work for contemporary survivors of AIDS loss.

### **The Effect of the Plague on Julian**

Articulating some crucial assumptions about the potential effects of the plague on Julian may help to establish the grounds for the belief that Julian may be understood as a survivor of plague-related loss. These assumptions flow from what is known about the magnitude and effect of plague loss on Julian's contemporaries as these are expressed in their writings. In addition, several of these assumptions are informed by the experience of twentieth century survivors of multiple loss, and it seems reasonable to expect that

their experiences may also capture certain aspects of Julian's experience.<sup>6</sup>

The first and most significant assumption is that *Julian would have been exposed to the physical horror of death on a large scale at a young age*. This assumption flows directly from two facts: first, Julian, who was born in 1342, would have been six or seven when the first plague epidemic arrived in England. Second, according to the best estimates available, we can hypothesize that Julian would have experienced the deaths from the plague of nearly half of the people that she knew.

Second, there is every reason to believe that *Julian would have experienced a diminished psychic capacity to absorb these deaths and to feel their effects*. In addition, *her mourning would have been impaired by disruptions of the normal customs for death and burial that accompanied the plague*. Hypothesizing these effects seems reasonable in light of the testimony to apathy and diminishment of feeling that is widely described in the chroniclers' accounts of the plague. It also seems reasonable because of the disruption in normal death rituals that characterized the first plague epidemic.

Third, there is every reason to expect that *Julian would have experienced*

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<sup>6</sup> Some readers may question the advisability of applying twentieth century research on survivors to Julian's experience of plague in the fourteenth century. I would argue that this comparison is appropriate based on the striking similarities I have observed between twentieth century accounts of multiple death experiences and the accounts of plague loss. Even within the twentieth century, survivors of widely varying disastrous situations, such as the holocaust, Hiroshima, the Vietnam war, AIDS loss and natural disasters, like the Buffalo Creek flood, appear to experience very similar effects. It would appear that post-traumatic stress and its symptoms seem fairly consistent across time. However, we must be careful to note as Lifton does that "*To observe common psychological responses of survivors... in no way suggests that the historical events themselves can be equated*" (original emphasis). It will be important in the present study, therefore, to observe both the similarities and differences that characterize the two forms of multiple loss we shall explore, namely AIDS-related multiple loss and plague-related multiple loss. See Robert Jay Lifton, "The Concept of the Survivor," in his book *The Future of Immortality and Other Essays for a Nuclear Age* (New York: Basic Books, 1987), 232.



*cumulative effects of multiple loss*, since she would have lived through several additional epidemics of the plague in addition to the first, great epidemic in 1348-9.

Fourth, there is also every reason to expect that *Julian's memories of these events would have been vivid and lasting*. This phenomenon is characteristic of survivors of post-traumatic stress, and as a plague survivor, Julian must have experienced a heightened recall of massive death.

Fifth, as all survivors do, *Julian would have encountered the question, "Why did I survive whereas so many others died?"* We have noted the presence of this question, for example, in the sermons of Thomas Brinton, her contemporary. There is no reason to expect that Julian would have been exempt from this question. Indeed, surviving several plague epidemics may have made this question even more urgent for Julian than for others who had less experience with the plague.

Sixth, it seems reasonable to believe that *Julian and her contemporaries would have lived with dread about potential recurrences of the plague* and have asked, in living through repeated outbreaks, whether God and the world were reliable. Experiencing repeated outbreaks may have led to a diminished capacity for hope.

Seventh, it also seems quite reasonable to assume from what we know about the social disruption caused by the plague that *Julian would have experienced ruptures in the fabric of her community as a result of the plague*. Undoubtedly, she would have experienced some absence of social support. Relationships are commonly strained in situations of multiple loss, as survivors attempt to cope with the magnitude of loss they have experienced. The presence of community disruption in the face of the plague was

reflected in abandonment of the sick and dying, and it is one of the most frequently noted effects in the chroniclers' accounts.

Eighth, *Julian may have experienced several psychological effects of the plague: a sense of foreshortened future, a death-dominated life, unresolved or incomplete mourning, a restricted emotional range, and temptations to despair.* We shall return to several of these issues in our analysis of Lifton's psychology of the survivor and explore evidence in Julian's text that may support their presence in her experience.

Ninth, *plague experiences may have heightened Julian's concerns with sin and salvation, as she would have been exposed to the dominant theological explanation for the plague in her day.* These concerns may also have been heightened by the feelings of shame and guilt that often accompany the experience of surviving multiple loss. The centrality of these concerns in the Long Text, in particular, makes this assumption seem quite reasonable.

Finally, *Julian's life seems characterized by a plethora of boundary situations.* Julian lived as an anchoress, she was a near death survivor and she was a woman who

experienced multiple deaths. In addition, she may also have survived childbirth.<sup>7</sup> Each of these situations would have situated her at the border between life and death and may have further contributed to the development of a survivor mentality on her part.

In an attempt to understand the significance of these assumptions for the development of Julian's theology and spirituality, let us now explore Robert Jay Lifton's psychology of the survivor. Understanding his work may help to elucidate further the impact of plague loss on Julian's life and theology.

### **Robert Jay Lifton's Psychology of the Survivor**

Psychiatrist Robert Jay Lifton's psychology of the survivor has been an invaluable resource in developing my understanding of Julian as a survivor of plague loss. The purpose of this section is to introduce Lifton's psychology of the survivor. In the next section, we shall apply this psychology to Julian as a plague survivor and use it to interpret the psychological impact of her vision.

Lifton has spent many years working with survivors of various trauma. His research in this field began in the sixties with his monumental work, *Death in Life*:

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<sup>7</sup> First, in this regard, it is important to note that the rite for becoming an anchoress mimicked a requiem. The bishop led the anchoress by the hand into her cell and the door was bolted from without. In many practical respects, therefore, the anchoress was understood to be "dead to the world." Second, I agree with the position of a number of scholars that Julian may have been a mother who lost a child in the plague. I base my support for this view on several facts. It seems quite likely that Julian may have married before the onset of the second plague epidemic and given birth to a child. She would have lived to a marriageable age after the first epidemic, and one result of the first epidemic was an increase in the number of marriages and births. Second, it also seems likely that Julian may have lost a child and possibly a spouse in one of the subsequent epidemics. The plagues of 1361 and 1369 were known to cause particularly heavy deaths among young men and children. Third, I do not find compelling evidence in the text to support the view that Julian was a nun. Fourth, I believe that the descriptions of the motherhood of Christ that occur in the text are quite compelling. I find it quite conceivable that they may reflect Julian's experience as a mother. However, it is important to note that there is no external evidence to support this view, nor is there likely to be any. Therefore, each reader must decide for him or herself how to interpret the textual evidence on this point.

*Survivors of Hiroshima*. In the course of this work, Lifton developed his five descriptive categories for understanding the psyche of survivors. Since that time, he has worked with Vietnam war veterans, survivors of the Buffalo Creek flood in West Virginia, concentration camp survivors and Nazi doctors. In each of these populations, Lifton has identified certain common psychological patterns that appear to be present in survivors of traumatic death, regardless of the particular cause of the death exposure. Let us consider these categories and explore their applicability for understanding Julian's experience and reflection upon it.

Lifton begins by offering a definition of the survivor. In his words, a survivor is "one who has encountered, been exposed to, or witnessed death and has himself or herself remained alive."<sup>8</sup> According to Lifton, survivors normally pursue one of two options. Either they confront the death immersion they have experienced and seek insight and healing or they confront the death immersion and respond with cessation of feeling or psychic numbing. He notes that, on the one hand, the pattern of response that is characteristic of survivors of death immersions is distinctive to that experience. On the other hand, in understanding this experience, it is possible to draw on other developmental phenomena such as separation, stasis and disintegration. The power of survivors' emotional experience derives from the psychological wedding of these two phenomena, trauma from massive death and painful experiences in development.

Lifton believes that five distinctive psychological themes characterize the psyche of survivors. The first is the presence of the *death imprint and associated death anxiety*.

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<sup>8</sup> Lifton, "The Concept of the Survivor," in *Future of Immortality*, 235.

The death imprint consists of “indelible images not just of death but of grotesque and absurd (that is, totally unacceptable) forms of death.”<sup>9</sup> He believes that for plague survivors these images would have included the grotesque and distinctive symptoms of the plague, including buboes, vomiting and spitting of blood and the terrible “pestilential odor” from bodies and breath of the ill. The perception of selective destiny in which some victims recovered and others did not would also have been a part of the plague’s death imprint.<sup>10</sup> According to Lifton, the death imprint is recalled with great clarity and immediacy many years after the original event. Survivors may have a sense of being bound by it and seeing all subsequent experiences through its lens. The death imprint derives psychological force from the convergence of two phenomena: the association of its constitutive imagery with prior experiences of separation, breakdown, and stasis and its association with the fear of death. It derives further force from feelings of guilt and self-blame that are often attached to it. As Lifton notes, in situations of overwhelming death:

One feels responsible for what one has not done, for what one has not felt and above all, for the gap between the physical and psychic inactivation and what one felt called upon (by the beginning image-formation) to do and feel.<sup>11</sup>

The term “inactivation” refers to the fact that there is an element of frustrated enactment associated with the death imprint: the survivor is haunted by a desire to replay the scenario of death in a way that would bring it to a more acceptable conclusion, whether

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<sup>9</sup> Ibid., 236.

<sup>10</sup> Lifton, *Death in Life*, 480-81.

<sup>11</sup> Robert Jay Lifton, *The Broken Connection: On Death and the Continuity of Life* (New York: Simon & Schuster, 1979), 171

“by preventing others from dying, taking bolder action of any kind, experiencing stronger compassion or pity or perhaps suffering or dying in place of the other or others. In that way, the hope is to be relieved of the burden of self blame.”<sup>12</sup> However, as Lifton notes rather ironically, actual recovery and relief from guilt depend much more upon survivors’ understanding and acceptance of their inability to respond more actively in times of traumatic loss.

The second distinctive psychological theme that characterizes the survivor is *death guilt*. Death guilt is epitomized by the survivor’s question: Why did I survive while others died? This guilt is directly related to the failed enactment described above. Survivors feel a responsibility and debt toward the dead because of their inability either to act in a way they would ordinarily have thought appropriate in a death situation or to feel the feelings they ought to have felt for the dying and the dead. Frequently, this guilt is also accompanied by a sense of shame for these failures. As Lifton poignantly puts it:

One could define the traumatic syndrome as the state of being haunted by images that can neither be enacted nor cast aside. Suffering is associated with being “stuck.”<sup>13</sup>

Those experiencing death guilt are often haunted both by unwanted dreams and intrusive waking images of “ultimate horror”: by a particular picture that summarizes, as it were, the horror and brutality of the death scenes they have witnessed. Again, survivors may experience two different results: they can remain “stuck,” doomed to replay these images

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<sup>12</sup> Ibid. Note the similarity between the latter two options here and Julian’s response to the vision of the crucified Christ described above in chap. 5, 122.

<sup>13</sup> Ibid., 172.

and their associated guilt or they can experience transformation around the image. Lifton notes that one form of transformation of the guilt feelings occurs through “religious visions of realization and moral growth through suffering.”<sup>14</sup> Unfortunately, survivors often feel guilt about their joy at having survived. As Lifton notes, there is an ethical quality to this pain. The existence of survivor guilt sensitizes us to the often unconscious feelings of responsibility we hold for our fellow human beings and our desire for their survival.

The third psychological theme characteristic of survivors’ experience is *psychic numbing*. This is a diminished capacity to feel that emerges in situations of trauma. Psychic numbing is a necessary psychological defense against overwhelming images and stimuli. It may be understood as a disconnection between cognitive images and the emotions that would normally accompany them. In essence, it constitutes an impairment of the ability to create symbols. In psychic numbing:

the self is severed from its own history, from its grounding in such psychic forms as compassion for others, communal involvement and other ultimate values. That is what is meant by the mind being severed from its own forms. And that severance, in turn, results in the failed enactment and guilt we spoke of before.<sup>15</sup>

In short, psychic numbing constitutes a dissociative phenomenon in which crucial components of the self are simply unavailable to the ego. For survivors, one particularly crucial challenge is to “hit upon” the right degree of psychic numbing: too much, and it is as if one is already dead. With insufficient numbing, in contrast, the survivor would

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<sup>14</sup> Ibid., 172.

<sup>15</sup> Ibid., 175.

continue to be overwhelmed by pain. Recovery from psychic numbing involves developing the capacity to feel again.

The fourth psychological theme characterizing survivors is, in many ways, the most complex. Lifton describes it as *the suspicion of counterfeit nurturance* and this phenomenon describes the conflicted feelings survivors hold about interpersonal relationships. On the one hand, survivors struggle with issues of autonomy. They feel the effects of their ordeal but are often reluctant to receive support. To do so is to acknowledge the impact of the trauma they have experienced. A second issue is contagion, and this has two aspects. First, survivors feel themselves marked by their experiences. Second, survivors are aware that others perceive them as tainted. These feelings may lead survivors to patterns of mistrust in relationships and to mutual antagonism and even avoidance of others.

Trauma affects survivors' perceptions of the nature of day to day life. Survivors may have a sense after trauma that the everyday world is counterfeit because it is a "moral inversion" of the traumatic world in which they have lived. Survivors may feel that they have come from a world in which living and dying "were divested of moral structure and lost all logic."<sup>16</sup> Living in such a world, survivors must decide either to reject it as counterfeit or to adapt to its inverted logic and survive. As Lifton notes, survivors can become paralyzed by these conflictual dynamics, or

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<sup>16</sup> Lifton, "The Concept of the Survivor," in *Future of Immortality*, 241. This phenomenon was particularly troubling for concentration camp survivors who "on entering the camp in the morning would have been dead by nightfall if they had adhered to all the ethical and moral standards of civilian life." William G. Niederland, "Psychiatric Disorders among Persecution Victims," *Journal of Nervous and Mental Diseases* 139 (1964): 458-74, 468; cited in Lifton, *Death in Life*, 487. The relationship between life and death often seemed random in the camps.



alternatively, survivors can transcend these conflicts and achieve an enhanced sensitivity to falseness, to counterfeit behavior of any kind, and an equally enhanced appreciation of what is authentic and fundamental in relationship to living and dying.<sup>17</sup>

In other words, survivors can come away from trauma with a deepened sense of what is authentic and inauthentic in both life and death.

The phenomenon of counterfeit nurturance is frequently associated with emotions of anger, even rage, and with such psychological phenomena as scapegoating and identification with the aggressor. Lifton understands these emotions as survivors' desperate attempts to maintain vitality, particularly when they feel that they are living among the annihilated. He notes that feelings of anger can help to displace guilt and anxiety and can be a helpful psychic lifeline for those who feel overwhelmed by images of death.

Lifton labels the final psychological dynamic characteristic of survivors *formulation*. This term describes survivors' struggles for meaning and sense of inner form in the face of the trauma they have experienced. There may be several aspects to this search: some survivors become "collectors of justice," seeking some acknowledgment of the crimes committed against them. They seek to re-establish a sense of a moral universe. Other survivors feel compelled to bear witness, to develop a survivor "mission" related to the injustices they have experienced.<sup>18</sup> The essential task of the survivor is to find meaning in the trauma, to recover the capacity to create symbols that is lost in the process of surviving. One of the most frequent ways to recover meaning

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<sup>17</sup> Ibid.

<sup>18</sup> This phenomenon is reflected, for example, in the efforts of Hiroshima survivors in the peace movement and in concentration camp survivors' involvement in the creation of the state of Israel.

that is lost in the process of surviving. One of the most frequent ways to recover meaning is through biological reproduction, which allows the survivor to contribute concretely to the continuance of life, a symbolic mode of immortality. The key to survival is to find ways to assert the continuity of life and the integrity of the self that are also true to the experience of death one has known. Survivors must find a way to grieve the losses they have experienced, to give form and significance to the death immersion, or else they risk stasis and entrapment in the mourning process. Typically, attempts to find meaning after death immersion require three elements: first, developing *a sense of connection*, of relationship both with people and with other aspects of the environment and psyche; second, developing *a sense of the symbolic integrity of one's life*, a sense that all of one's life, including the death immersion, has meaning; and third, developing *a sense of movement*, of development and change rather than of stasis.<sup>19</sup>

This summary of Lifton's theory captures the essential aspects of his psychology of the survivor. As previously noted, this theoretical understanding of the survivor has taken shape through Lifton's study of people surviving a number of painful holocausts in this century, as well as his reflection on historical holocausts. Let us now explore the usefulness of these views in developing an understanding of Julian's life and vision as it may have been affected by the Black Death.

### **Julian as Survivor**

In this section, two theses about Julian and her life will be considered. The first thesis is that Julian may be better understood through a focus on her experience as a

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<sup>19</sup> Lifton, *Death in Life*, 367.

survivor of plague loss. The second thesis is that Julian's vision may be understood as a creative act of the religious imagination that enabled her to heal from survivor trauma. This vision and her reflection upon it allowed her to give inner form and significance to the death immersion that she had experienced and, therefore, to the rest of her life in relationship to it.

Developing a more specific understanding of Julian as a plague survivor helps to refine our understanding of her life and work. First, understanding Julian as a survivor situates her concretely in her fourteenth century context, for it makes explicit the effects of the massive death encounter she experienced. Second, understanding Julian as a survivor provides us with a way of integrating her psychological experience with her theological and spiritual insights. The analysis will allow us to explore how her theological ideas may have been shaped by the particular feelings and needs she undoubtedly experienced in her encounter with massive death. Conversely, it will demonstrate ways in which she drew on her religious understandings to heal from the more painful aspects of her experience of loss.

Understanding Julian as a survivor also makes explicit her usefulness as a resource for AIDS survivors. It paves the way for other survivors to gain insight from her psychological and religious experiences and reflections, for it allows them to understand how her experience with massive death may have influenced the development of her theology and spirituality.

With these thoughts in mind, let us now turn to a more specific exploration of Julian's experience in light of Lifton's work.

### The Death Imprint and Death Anxiety

The purpose of this section is to describe how the form and effect of Julian's vision were influenced by her experience of death anxiety and the death imprint. The assumption guiding this argument, following Lifton, is that Julian would have experienced both death anxiety and the death imprint as a result of her exposure to massive death in the plague. The chroniclers' accounts describe conditions that would have led to such phenomena, and Lifton himself describes the features that may have constituted the typical aspects of a plague-related death imprint.<sup>20</sup>

Julian experienced sixteen visions. The first fifteen occurred on May 8<sup>th</sup>, while the sixteenth took place on the following evening. In the first chapter of the Long Text, Julian described in summary form the nature of the visions and the meaning of each. The primary focus of the visions is the Crucified Christ. Through her vision of the crucifixion and her interaction with it, Julian developed her theology of redemption and salvation. Other visions on the first day are concerned with the rightfulness and excellence of creation, the rewards of heaven, the preservation of the soul in love, Christ's delight in the passion, Christ's love for humankind, the nature of prayer, and the honor due to the saints, especially the Virgin Mary. The sixteenth vision is of the Trinity dwelling in Christ within the human soul, preserving it in love and protecting it from harm.

Julian's prayers prior to her vision suggested that she shared two key traits with survivors: first, identification with the dying and, second a heightened awareness of her own death. The former is reflected in her prayer to be one with those at the foot of the

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<sup>20</sup> See p. 181 above.

cross and to have knowledge of the bodily pains of Christ's passion.<sup>21</sup> The latter is reflected in her prayer for "a grave sickness even to the point of death . . . in this sickness [she] desired to have all manner of pains both in body and spirit that [she] should have if [she] should die."<sup>22</sup> It seems quite likely that Julian had anxiety about her eventual death. One reason why she prayed for a sickness unto death was that she wanted the sickness to prosper her in her own death, to enable her to withstand the temptations from the fiend that she anticipated at her final hour.<sup>23</sup> Undoubtedly, Julian witnessed the deaths of many in the plague who were unprepared spiritually for death. Fearing for her salvation, she wanted a "dry run," an opportunity to encounter death so that she might prepare herself in advance for its rigors.<sup>24</sup>

In addition, there is evidence in the text to support the notion that Julian suffered from anxiety about her potential for premature death and an unfulfilled life. This, also, is a characteristic of survivors marked by a death imprint. Prior to her illness, she noted that "I was certain that I would die, which was both a wonder and a partial sadness. . . ."<sup>25</sup> Then, with the onset of her illness, she noted that "being still young, I thought it a great

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<sup>21</sup> Julian of Norwich, *Revelation of Love*, chap. 2, 4.

<sup>22</sup> *Ibid.*, 4-5.

<sup>23</sup> *Ibid.*, 4.

<sup>24</sup> In light of this, it is important to recall that the association of the plague with unprepared death was, as Horrox notes, "one of its particular terrors." Horrox, *Black Death*, 245. This fear is addressed in the literature of the day, including the famous *Ars Moriendi*, a fifteenth century French treatise on the art of dying well. See also p. 172 above.

<sup>25</sup> *Ibid.*, chap. 8, 18

sadness to die,”<sup>26</sup> Clearly, Julian had ambiguous feelings about her own death, and her reluctance to face it is evident in the text.

Julian’s experience of her vision provided her with an opportunity for healing from the impaired psychological dynamics characteristic of survivors of massive death. Healing occurred in the following way: Julian’s vision of the crucified Christ may be understood as a type of death imprint, different from the death imprint that arose from her plague experience. Her strenuous, and at times painful, interaction with her vision of the crucifixion allowed her to heal from the destructive impact of her plague-related death imprint. Julian’s account of her experience described clearly how she was able to participate effectively in Christ’s death. Her active engagement with the death imprint of the crucifixion may have relieved her of guilt associated with the “failed enactment” captured in the original, plague-related death imprint. Her efficacious interaction with the vision, therefore, provided her with a chance to overcome both the damaging effects of the earlier death imprint and the death anxiety associated with it.

Central to this thesis is the argument that Julian’s vision of the crucified Christ may be thought of as a death imprint. To use Lifton’s language, this vision represents an “image of death” that is both “grotesque” and “absurd.”<sup>27</sup> The grotesque quality of the imagery resides in the painful effects of the inhumane suffering that Christ experienced and that Julian described in excruciating detail. These effects include the copious

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<sup>26</sup> Ibid., chap. 3, 5.

<sup>27</sup> See p. 181 above.

bleeding of Christ's head and body;<sup>28</sup> the contemptuous treatment of the dying Christ, including the spitting, soiling and buffeting of his body;<sup>29</sup> the discoloration and spoiling of his fair appearance;<sup>30</sup> the drying of Christ's body;<sup>31</sup> and the separation of Christ's skin from his skull.<sup>32</sup> Further, one may understand this death as "bizarre, unnatural, indecent and absurd."<sup>33</sup> These qualities, in Julian's view, derived from the fact that Christ experienced no human comfort in the midst of this painful death,<sup>34</sup> that he who was reduced to nothing was God,<sup>35</sup> and therefore, that he who was highest and most worthy was completely humiliated and utterly despised in this shameful death.<sup>36</sup> It is clear, therefore, that there was a degree of unacceptability and injustice in this death as Julian experienced it.

Clearly, also, Julian experienced death anxiety as she witnessed this vision, for she stated that she regretted praying the prayer that resulted in it. As she noted:

Little did I realize what pain I asked for and like a wretch I regretted it, thinking to myself, if only I had known what it were like, I would never have prayed for it. For I thought these pains of mine surpassed even those of bodily death.<sup>37</sup>

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<sup>28</sup> Ibid., chap. 7, 14.

<sup>29</sup> Ibid., chap. 10, 21.

<sup>30</sup> Ibid., chap. 10, 21 and chap. 16, 35.

<sup>31</sup> Ibid., chap. 16, 35.

<sup>32</sup> Ibid., chap. 17, 37. It would appear, also, that Julian's memories of her vision were characterized by the same vividness of recall that accompany other survivors' descriptions of their death imprints. See Lifton, *Death in Life*, 482.

<sup>33</sup> Lifton, *Death in Life*, 480.

<sup>34</sup> Julian of Norwich, *Revelation of Love*, chap. 17, 38.

<sup>35</sup> Ibid., chap. 18, 40.

<sup>36</sup> Ibid., chap. 20, 43.

<sup>37</sup> Ibid., chap. 17, 38.

for it. For I thought these pains of mine surpassed even those of bodily death.<sup>37</sup>

Therefore, in witnessing this suffering, Julian had doubts about her ability to survive the pain associated with it. Nevertheless, she remained with the vision, to her great satisfaction.<sup>38</sup>

Beside her ability to interact with the vision efficaciously, another important factor contributed to Julian's efforts to heal from the damaging effects of her earlier death imprint. In staying with the crucified Christ, despite the anxiety and pain that it caused her, Julian was able to move consciously through death to new life. This movement occurred in both the form and content of her experience. With regard to the content, Julian described in the eighth "showing" of the vision how Christ's painful death was changed into an image of life and glorification.

For at the very moment when it appeared to me that life could not be sustained and that the vision must of necessity come to an end, suddenly, as I still looked at the cross, I saw that his blessed face had changed. It was this change that at once affected me: for I was now as glad and happy as could be. Our Lord brought to mind the words: 'Where now is there any point in the pain or in your grief?' In my new-found joy, I saw that in this life, in our Lord's plan, we are with him on his cross, dying with him in our pains and passion; when of a sudden his face will change in our sight, and then we will be with him in heaven. There will be no time between one state and the other: suddenly, we will be brought to his joy.<sup>39</sup>

Here Julian described how Christ's passage from death to new life was instantaneous.

The forcefulness of this passage from death to new life took on even greater meaning for Julian because her vision occurred when she herself was poised between

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<sup>37</sup> Ibid., chap. 17, 38.

<sup>38</sup> We shall return to this issue of her efficacious interaction with the vision immediately below in our discussion of death guilt.

<sup>39</sup> Ibid., chap. 21, 44-45.



death and life. That is, Julian's vision had even greater effect because it occurred in the context of a near death experience. Julian was at the point of actual death when she received her vision, yet she did not die. The force of the movement through death to life in the vision gained added strength from this fact. Her return to life following her encounter with death in her experience and vision undoubtedly provided her with healing from death anxiety. However, even after the first part of her vision, Julian's sense of her vulnerability to death remained strong. Her belief in her power to withstand the forces of death was not established on firm footing until her final vision on the next day in which Christ assured her that she would not be overcome.<sup>40</sup> It was the confidence that she gained from this final showing that truly empowered her in her "survivor mission" of reflecting and writing on her vision for the sake of her "even Christians."<sup>41</sup>

The argument, therefore, is that Julian's visionary experience of the crucified Christ provided her with a vehicle for effectively participating in a grotesque and absurd death. The effectiveness of her participation provided her with a measure of healing from the painful encounter with death that she had experienced in the plague. Further, her ability to understand Christ's death as painful, and yet as purposeful and yielding of new life may also have provided a measure of healing.

#### Death Guilt and Identification with the Dead

Julian's ability to remain with the dying Christ, despite the pain this caused her,

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<sup>40</sup> Ibid., chap. 68, 151.

<sup>41</sup> Julian used this term to refer to her fellow Christians. It is derived from a word meaning "hold together," and thus, it suggest the unity she shares with fellow believers.

provided her with a sense of efficacy that may have counteracted the death guilt associated with her experience of the plague. This achievement was an important aspect of the healing arising from her vision.

In his discussion of death guilt, Lifton states that:

Death guilt begins . . . in the gap between that physical and psychic inactivation [survivors experience] and what [they] feel called upon to do and feel. That is one reason the [death] imagery keeps recurring, in dreams and in waking life.<sup>42</sup>

A key element in the healing that Julian experienced through her vision was her ability to remain compassionately with the dying Christ, despite the emotional pain she experienced in observing Christ's sufferings. Julian's ability to remain with Christ, despite his and her pain, was a departure from her earlier death encounter in the plague. She, like many, may have been immobilized or even have fled in the face of massive death. Julian's ability to remain with the vision of the dying Christ becomes central to the development of her theology, for she derives her twofold anthropology directly from this experience.

Julian described her conscious decision to remain with the dying Christ in Chapter 19 in the Long Text. Previously, she had described the tremendous pain she experienced in seeing Christ suffer. Then she told the reader how she wanted to look away from the cross. In fact, as she contemplated this action:

[a] suggestion came to mind, just like a friend inviting me: 'Look up to heaven, to his Father.'<sup>43</sup>

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<sup>42</sup> Lifton, *The Future of Immortality*, 237.

<sup>43</sup> Julian of Norwich, *Revelation of Love*, chap. 19, 41.

While Julian did not say it explicitly, she implied that this suggestion to look away from the cross represented a temptation by “the fiend.” Had she succumbed to it, Julian may have escaped the healing potential present in remaining with the vision. However, after considering the suggestion:

[she] was sure in her faith that there was nothing between the cross and heaven that could draw her aside.<sup>44</sup>

She continued:

Either I must look up or else answer for myself. I did so inwardly with every power in my soul, saying [to the suffering Christ], ‘No I may not, for you are my heaven.’ I said this because I would not look up; for I had rather borne that pain until Doomsday than come to heaven other than by him.<sup>45</sup>

Julian went on to elaborate the effect of this choice upon her spirit.

Thus I was taught to choose Jesus to be my heaven, whom at that time I could only see in pain. . . . And ever since then, this has always been my comfort, that, by his grace, I chose Jesus to be my heaven throughout this time of passion and sorrow. And that lesson has served me that I should do so evermore, choosing only Jesus for my heaven in weal and woe.<sup>46</sup>

Julian’s decision to remain with the dying Christ constitutes a significant turning point, and it reflects Julian’s triumph over death guilt. Julian’s choice to remain compassionately with the dying Christ constituted her successful enactment in the face of the death imprint represented in her vision. The sense of efficacy that she achieved through this choice is central to her healing from the sense of inactivation that she may

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<sup>44</sup> Ibid.

<sup>45</sup> Ibid.

<sup>46</sup> Ibid.

have experienced in her earlier encounters with death.

A second aspect of her visionary experience may also have provided her with relief from the burden of guilt and self-blame characteristic of survivors and renewed her “right to live.” Julian’s encounter with Christ, who freely chose to die in order that she could live, may have provided her with relief from the survivors’ question, “Why did I survive whereas others died?” Christ’s willingness to suffer on her behalf is expressed in the ninth showing. Christ asks Julian if she is satisfied that he suffered for her. When she responded affirmatively, Jesus said,

If you are pleased, then I too am pleased. This is my joy, my bliss, my endless liking that I was ever able to suffer for you. For truly, if I could have suffered more, I would have suffered more.<sup>47</sup>

And again in the Tenth Showing, she wrote:

[O]ur good Lord gently spoke, ‘Lo, how I loved you . . . To understand to the full these words of his, ‘See how I love you,’ it was as if he were to say: ‘Lo how I loved you. Behold and see that I loved you so much that before ever I died for you, I would die for you; and now I have died for you and willingly suffered all that I may. And now is all my bitter pain and all my hard travail turned into endless joy and bliss to me and to you.’<sup>48</sup>

Thus, Julian believed, as a result of her vision, that Christ chose freely to suffer on her behalf and that his suffering and death were a source of life and joy for her. Christ’s death enabled her both to live and to live with a sense of freedom and joy. Therefore, through Christ’s willingness to die for her, she was relieved from the burden many survivors bear of living halfheartedly because of the guilt they feel for their survival.

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<sup>47</sup> Ibid., chap. 22, 46.

<sup>48</sup> Ibid., chap. 24, 50-51.

Julian's encounter with the Christ, who chose to suffer on her behalf, provided her with an experience of meaningful death. This experience surely must have provided a sharp contrast psychologically to the arbitrariness of the many plague deaths Julian would have witnessed. At the same time, the psychological effect of Christ's willingness to suffer and die for Julian's sins, was strengthened through Julian's awareness, derived from her vision, that Christ did not blame her for her sins. For, while Christ brought to Julian's mind the fact that she was not exempt from sin,<sup>49</sup> Julian also realized in the course of her vision that God does not respond to our sins with anger or blame.

God also showed that sin shall cause us no shame, but will even be accounted to our honour. For just as every sin is answered in reality by a particular pain, so for every sin that same soul is given joy by love. And as different sins are punished by various pains in accordance with their gravity, so will they be rewarded in heaven by joys that differ according to the pain and sorrow they caused that soul on earth.<sup>50</sup>

Knowing that God did not blame her for the sin that resulted in his death must have relieved Julian from the considerable weight of self reproach and shame that she may have felt as a survivor of the plague. For, if the greatest suffering she has known -- Christ's passion and death -- can be turned to joy, the same must also be possible for the suffering and death she had known earlier in the plague.

In summary, therefore, Julian's vision freed her from death guilt in two ways: first, through the opportunity it provided her to participate efficaciously in death, and second through the assurance she received from Christ that God did not blame her for

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<sup>49</sup> Ibid., chap. 37, 72.

<sup>50</sup> Ibid., chap. 38, 73.

causing Christ's death. Julian learned that Christ's atonement for sin freed her from the need to atone.

### Psychic Numbing

Psychic numbing is the third trait Robert Jay Lifton describes as characterizing the psychology of survivors. Psychic numbing represents the survivor's diminished capacity to feel. It arises in situations of trauma, where it appears that the survivor's capacity to form mental symbols of the death experience is impaired. It is as if survivors retain the capacity to form cognitive images of the horror they are experiencing, yet disconnect these images from the feelings that would normally accompany them. While viewing the dying, survivors seemingly tell themselves: "If I feel nothing, death is not taking place" and/or "I see you, but I am not related to you or your dying."

Lifton believes that in psychic numbing the self becomes severed from such psychic forms as compassion for others, communal involvement and other ultimate values. The end result of psychic numbing is a sluggish despair characterized by chronic depression and a constricted life space that is often covered over by rage and mistrust. The survivor takes on the identity of the dead as a result of the experience of psychic numbing, for he or she lives a sort of "half life" rather than a vital and fulfilling life.

It is possible that Julian may have experienced the deleterious effects of psychic numbing prior to her vision. Of course, evidence for this is limited. However, the fact of her illness prior to her vision suggests that she may have been physically affected by grief. Second, her prayer for a sickness unto death suggests that she may have identified with the dying to the point of wishing to die herself. These are speculations, but it does

seem clear that Julian felt a vitality and joy for living after her vision that seems discontinuous with the brief glimpses we obtain of her life before the vision.

My hypothesis is that Julian's vision provided her with an opportunity to heal from psychic numbing. She experienced healing because she allowed herself to feel fully the compassion and empathy she held for the dying Christ. As we have already noted, Julian experienced these feelings at some personal cost, because they were much more intense than she anticipated.<sup>51</sup> Nevertheless, the fact that she remained with the vision despite her pain is evidence that she did not dissociate from her feelings of compassion for the suffering Christ. Julian's ability to remain with these feelings allowed her an opportunity to move through grief to a more fulfilling life. Two outcomes of Julian's vision, therefore, were an increased willingness to live and an increased capacity to experience joy in God's love for her.<sup>52</sup> The existence of these traits in the wake of her vision provide evidence for Julian's healing from the dampening effects of psychic numbing.

#### Counterfeit Nurturance

Counterfeit nurturance is the term Lifton has coined to describe the effects of surviving trauma on interpersonal relationships. These effects may range from struggles with autonomy, to concerns with contagion and consequent mistrust, to increased sensitivity to authenticity and inauthenticity in relationships, to rage in the face of

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<sup>51</sup> See p. 191 above.

<sup>52</sup> On the former, see especially chap. 64. For the latter, see chap. 77, 168. "This place is a prison; this life is a penance. Yet it is a remedy that he wants us to enjoy. For the remedy is that our Lord is with us, keeping and leading us into the fullness of joy."

scapegoating.

There is little evidence in the text to support the notion that Julian suffered from the degree of anger and mistrust in interpersonal relationships that sometimes characterizes survivors of multiple loss, for the text reveals little about Julian's relationships. Existing evidence does suggest that Julian was a woman of deep compassion who felt great empathy for her fellow Christians. However, it is interesting to speculate about Julian's choice to live as an anchoress. In making this choice, she effectively removed herself from the social sphere. Was she at all motivated by a sense of contagion, or did this lifestyle provide her with the time and means to engage in her survivor "mission" of sharing the fruits of her vision with others? Unfortunately, the text does not allow us to decide between these alternatives.

There is some evidence in the text, however, to suggest that Julian may have experienced life prior to her vision as counterfeit, that is, as lacking in authenticity. Julian did tell us, for example, that before her vision, she

had a great longing and desire, by God's gift, to be delivered from this world and this life. Frequently, [she said] I witnessed the woe that is here and knew the well-being and bliss that is there. And even if there were no other pain in this life apart from the absence of the Lord, sometimes this alone seemed to me more than I could bear. And this made me mourn and long more eagerly, and also my own wretchedness, sloth and very weakness made me reluctant to live and labor on as I knew I should.<sup>53</sup>

Julian, therefore, appeared to experience life before her vision as tiresome and drab.

Perhaps Julian's lack of enthusiasm for life may have motivated her to pray for a sickness unto death. One wonders, also, if the pre-plague spirituality expressed in her prayers was

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<sup>53</sup> Ibid, chap. 64, 142-43.



an attempt on her part to seek an enhanced appreciation of what was truly authentic in living and dying.

As a result of her vision, Julian was somewhat relieved of her sense of this present life as counterfeit, for Julian saw more possibility for joy in daily life through God's sustaining love. However, Julian seems very much a child of her age in one respect: it does appear that she awaits the hope of final bliss in the life to come. That is, her other-worldly eschatology causes her to minimize the joys of the present life. The overwhelming impression one receives from the text, therefore, is that Julian believed that this present life pales in comparison with the life of the world to come.

#### Formulation

The final psychological characteristic Lifton has identified in survivors is formulation. Lifton uses the term to describe the way in which recovery from the trauma of multiple loss occurs as survivors are able to find meaning in their experience of death and dying and to make sense of trauma. He notes that survivors frequently undertake a mission, and Julian's efforts to write down and disseminate the contents of her vision may be understood in this way. Her efforts take on particular significance because first, Julian's text was the first written in English by a woman and second, she was at some risk of being condemned as a heretic for writing it. Her courage in producing this work is thus quite evident.

Julian's vision represented a creative attempt to give form and meaning to the experience of painful and absurd death. As a result of it, Julian achieved the symbolic immortality which Lifton states that survivors seek, for Julian emerged from her vision with Christ's assurance that she would not be overcome by sin and death. Freed from

anxiety about her death and salvation, Julian was able to devote herself as an evangelist to sharing the good news of God's love. Her vision, therefore, represented a confrontation with death, a reordering of her emotions and imagery, and a renewal of a sense of life's meaning and vitality. Further, Julian's attempts to find meaning through her vision provide evidence for the three traits Lifton notes as crucial in survivors' attempts to make meaning. First, Julian experienced a heightened sense of connection both to God and to her fellow Christians as a result of her vision. Second, Julian emerged with a greater sense of symbolic integrity, and she continued to develop this through her long-term reflection and writing on her vision. Finally, she was enabled to "move forward" through life. No longer paralyzed or robbed of vitality through mourning, she was able to embrace the life of a theologian and counselor.<sup>54</sup> Julian's vision, therefore, was a potent source of transformation, one which provided her with integrity, purpose and a new sense of her vocation.

In summary, therefore, Lifton's psychology of the survivor provides us with a useful schema for understanding Julian's life and experience prior to, during, and after her vision. Let us now examine more closely the character of Julian's theology to see what it may offer to other survivors of massive death.

### **"All Shall Be Well"**

To this point in our analysis of Julian's text, our primary concerns have been historical and psychological. That is, we have attempted to understand how Julian's work emerged in a particular context and how characteristics of that context may have

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<sup>54</sup> Lifton, *Death in Life*, 367 describes the sense of connection, the sense of symbolic integrity and the sense of movement as aspects of formulation.

influenced her development and vision in particular ways. In short, we have been concerned to a great degree with meanings lying “behind” the text.

As David Tracy points out, however, there is another aspect to the work of textual interpretation that demands our attention. This is the work of determining “the meaning ‘in front of the text,’ that is, that way of perceiving reality, that mode of being-in-the-world which opens the text up for the intelligent reader.”<sup>55</sup> For religious texts, this work of interpretation requires us to specify the particularly religious manner of being in the world that is proposed in the text.<sup>56</sup>

In Tracy’s view, authentic religious language “re-presents that basic confidence and trust in existence which *is* our fundamental faith, our basic authentic mode of being in the world.”<sup>57</sup> Religious texts do not merely re-present that faith, however. They provide a vision that allows us to see the implications of this faith for our ordinary lives. They encourage us to live “with explicit faith, with complete trust and with unrestricted love.”<sup>58</sup> In short, they

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<sup>55</sup> Tracy, *Blessed Rage for Order*, 51.

<sup>56</sup> Tracy describes the task of interpreting the meaning “in front of the text,” the referent of the text, as a truly hermeneutical task. He notes that interpreters seeking to understand a text must attend both to the “sense” of the text and the “referents” of a text. The sense refers to “the internal structure and meaning of the text as that structure can be determined through the ordinary methods of semantic and literary-critical inquiry.” The referent, in contrast, is “that way of perceiving reality, that mode of being-in-the-world which the text opens up for the intelligent reader.” For religious texts, the referent expresses a religious way of looking at reality. For example, the referent or existential meaning of the New Testament affirmation that “Jesus is the Christ” is that “one can now live as though in the presence of a gracious God.” Tracy borrows this particular interpretation of the New Testament affirmation from Herbert Braun. In elaborating his distinction between the sense and the referent of the text, he cites an unpublished manuscript by Paul Ricoeur. See Tracy, *Blessed Rage for Order*, 52.

<sup>57</sup> *Ibid.*, 134 (original emphasis).

<sup>58</sup> *Ibid.*

ask us to allow the limit experiences of trust and confidence in the final graciousness of reality itself to provide the basic orientation to our lives.<sup>59</sup>

In the course of Julian's vision, Christ provided her with a now famous reassurance: "Sin is necessary, but all shall be well. All shall be well; and all manner of things shall be well"<sup>60</sup> This statement certainly exemplifies Tracy's notion of a fundamental religious vision and acceptance of it is central to Julian's theology. A primary question of textual interpretation, therefore, is articulating the grounds for Julian's confidence that all shall be well. What was it in Julian's vision that provided her with the encouragement to adopt this degree of trust?

In responding to this question, we shall explore two aspects of Julian's thought. First, we shall examine her theology. What symbols, metaphors and images underlie her understanding that all shall be well? How does she articulate the basis for her trust? Second, we shall explore Julian's spirituality. What, in Julian's view, allows believers to live into these understandings? How may we be drawn beyond ourselves and our finitude towards an unshakable confidence in life's trustworthiness, even in the face of the daily disappointments that seem to belie it? Attention to each of these aspects of religious life - the cognitive and the experiential -- will provide us with important information about Julian's religious synthesis.

### Julian's Theology

The starting point for Julian's theology is an understanding of God. In Julian's view, God is the ground of all existence and God's nature is love. In fact, apprehending

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<sup>59</sup> Ibid.

<sup>60</sup> Julian of Norwich, *Revelation of Love*, chap. 27, 55.

God's essential nature as love was one of the most surprising insights Julian received. For, through her vision, Julian realized that, contrary to the religious teaching of her day, God is not angry, and that if God were to become angry and to withdraw love from us, we should not survive:

This was a high wonder to the soul which was shown continually in all the revelations and beheld with great diligence: that our Lord God of his very nature, may not forgive since he may never be angry – for that would be impossible. This is what was shown: our whole life is grounded and rooted in love, for without love we may not live.<sup>61</sup>

Love provides the foundation for life, therefore, and understanding God's essential nature as love undergirds Julian's development of all other doctrines.

Besides being rooted in her understanding of God as love, Julian's ability to affirm that all shall be well despite the reality of sin appears to be grounded in five traditional Christian doctrines: creation, redemption, anthropology, incarnation and eschatology.

Julian's view of *creation* derived from her vision of the hazelnut.

At the same time, he showed me something small, about the size of a hazelnut, that seemed to lie in the palm of my hand as round as a tiny ball. I tried to understand the sight of it, wondering what it could possibly mean. The answer came: 'This is all that is made.' I felt it was so small that it could easily fade to nothing; but again I was told: 'This lasts and will go on lasting forever because God loves it. And so it is with every being that God loves.'<sup>62</sup>

Through contemplating this vision, Julian learned three things about the nature of God's creative work: first, that God has made everything that is made, second, that God loves

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<sup>61</sup> Ibid, chap. 49, 96.

<sup>62</sup> Ibid., chap. 5, 9-10.

everything that is made, and third, that God keeps everything that is made. Further, Julian learned that God's love is as strong for great things as it is for small and humble things,<sup>63</sup> and she experienced that we are kept whole and safe by God regardless of whether our feelings confirm this or not.<sup>64</sup>

Perhaps the most remarkable and praiseworthy aspect of God's creative work, however, is its efficacy. This quality was captured in Julian's use of the word "rightful" to describe God's creative work.

Rightfulness is when something is so good that it may not be better than it is; and God himself is most rightfulness and his works are rightfully done as they are ordained from without beginning by his high might, his high wisdom and his high goodness. And right as he ordained it to the best, right so he works continually and leads it to the same end; therefore, he is always pleased with himself and all his works.<sup>65</sup>

Rightfulness describes the absolute efficacy of God's work.

Julian's unshakable confidence in the rightfulness of creation contributed greatly to the optimistic tone of her theology and to the facilitation of trust. Julian believed, for example, that the rightfulness of God's creative work embraced even those things which may appear evil to us.

While to us some deeds may seem well done, others evil, this is not so in God's sight. For since all things have their ground in God's making, so all that is done belongs to God's doing.<sup>66</sup>

In Julian's view of creation, therefore, all that is done is well done, since God does all.

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<sup>63</sup> Ibid., chap. 32, 62.

<sup>64</sup> Ibid., chap. 15, 34.

<sup>65</sup> Ibid., chap. 35, 68.

<sup>66</sup> Ibid., chap. 11, 26.

This affirmation leads naturally to a consideration of *sin and redemption*. Julian's views on sin include several key points. She believed, first, that sin has no being. While regarding the revelation about God's creative work, Julian did not see sin. Thus, she concluded that "sin is no-deed, for in all this sin was never shown."<sup>67</sup> Sin, therefore, is known mainly through its effects. Sin is

everything that is not good, and [includes] the shameful despising, the utter humiliation that [Christ] bore for us in this life, and his dying and the many pains that all his creatures also suffer; both in spirit and in body<sup>68</sup>

Sin, therefore, is the cause of pain. Julian also believed that sin is a source of rupture within human nature. Julian understood this rupture to exist between the higher and lower nature of humanity or between what Julian referred to as our substance and sensuality.

Julian used the term "substance" to describe the existence of divinity within the human soul.

And thus the human soul is made of God and in the same point is knit to God. And thus I understand that the soul is made of nothing, that is to say, it is made but not from anything that is made. It is like this: when God would make the body, he took the slime of the earth, that is material which is mixed and gathered of all material things, and in this way he made our body. But as to the making of our soul, he took nothing: he simply made it. And so is our made-nature rightfully oned with its Maker, who is substantial nature, unmade: that is God.<sup>69</sup>

Julian believed, therefore, that our soul is made of the very substance of God. It is this part of our being that Julian referred to as our "higher" nature. At the same time,

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<sup>67</sup> Ibid.

<sup>68</sup> Ibid., chap. 27, 55.

<sup>69</sup> Ibid., chap. 53, 118.

however, humans also have a “lower” nature which Julian referred to as our “sensuality.”

According to Grace Jantzen, she used this term to describe

all of our psychology and physicality as individual human beings: our capacities for perception in sight, hearing, touch and so on, our whole sensory consciousness and our capacity for action. In other words, sensuality refers to our existence as psychosomatic beings in a physical world. [Therefore, while] . . . our substance is the substance of being itself; our sensuality individuates us, making each of us one among many beings.<sup>70</sup>

Jantzen also rightly notes that the distinction between substance and sensuality is not equivalent to a dualistic distinction between body and soul. Sensuality is an embodied quality, but it relates to the union between the body and soul and cannot be equated with the body alone. As she puts it, “sensuality relates to the union of consciousness with embodiment.”<sup>71</sup>

The rupture within humans between the substance and sensuality, between our higher and lower natures, came about through Adam’s sin, which Julian understood as “the greatest harm that was ever done or ever shall be, until the world ends.”<sup>72</sup> Despite the existence of this great harm, however, the rightfulness of God’s creative work also

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<sup>70</sup> Jantzen, *Julian of Norwich*, 142.

<sup>71</sup> Ibid., 143. Julian experienced this two fold aspect of human nature in the eighth showing when she refused to look away from the cross. She expresses this in chap. 55 of the Long Text. This experience provides the foundation for the development of her anthropology.

<sup>72</sup> Julian of Norwich, *Revelation of Love*, chap. 29, 58. Julian used the term “Adam’s sin” to represent humankind’s fall or “first sin.” In the Parable of the Lord and Servant, Julian described this fall literally and metaphorically. In attempting to do the Lord’s will, the servant stumbles and falls. This fall is not a deliberate turning away from God; instead, it appears to be a consequence of human vulnerability. The servant stumbles because of his undue haste in attempting to satisfy the Lord’s request. Thus, the fall comes about not through disobedience, but through a desire to please that results in imprudent haste. Julian also described Adam’s fall as a movement from life to death. Birth into the world, therefore, is a form of fall. The saving nature of Christ’s birth compensates for the pain of Adam’s birth. See chapter 52 of the Long Text for a discussion of Adam’s fall.



applies to the work of the redemption. Julian believed that the work of redemption, “the re-making”<sup>73</sup> of humans through Christ’s passion and death is “more pleasing to God and honors humankind’s salvation more, without comparison, than any harm that ever came from Adam’s sin.”<sup>74</sup> Through the work of redemption, God “made well the greatest harm,” therefore, this knowledge provides a basis for Julian’s faith that God shall make well all that is less.”<sup>75</sup>

Through her vision, Julian also came to a somewhat startling conclusion for her time, namely, the view that God’s love is never broken toward us when we sin.

Inasmuch as his love is never broken towards us when we sin, so does he will that it is never broken within ourselves or toward our fellow Christians; rather we should hate the sin itself but endlessly love every soul as God loves it.<sup>76</sup>

Thus, God’s love remains constant and can provide grounds both for self love and love of neighbor.

On the basis of her revelation, Julian appeared to conclude, therefore, that sin is an inevitable part of human existence. When speaking of sin, she stated, “In this life we may not keep ourselves from sin as holy and fully clean as we shall be in heaven.”<sup>77</sup> Then, as Denise Nowakowski Baker notes, “given the fact of sin, she explores its function in the divine plan and God’s disposition toward sinners now and at the end of

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<sup>73</sup> Ibid., chap. 29, 58.

<sup>74</sup> Ibid.

<sup>75</sup> Ibid. Julian also contrasted the efficacy of God’s action in creation and redemption with the activity of “the fiend.” The fiend has the misfortune of seeing souls escape him continually “for all that God allows him to do turns to our joy, yet to him it is a constant source of shame and woe.” See chap. 13, 30.

<sup>76</sup> Ibid., chap. 40, 78.

<sup>77</sup> Ibid., chap. 52, 115.

time.”<sup>78</sup> Julian concluded that sin purges us and “makes us know ourselves as we ask for mercy.”<sup>79</sup> Sin provides us with knowledge of our limitations – it makes it possible for us to know “that we may not stand for a twinkling of an eye without being kept in grace, and reverently clinging to God, trusting only in him.”<sup>80</sup> Further, despite the fact that sin is a great source of pain to us, through the efficacy of God’s work in redemption, sins will be rewarded in heaven by joys that are proportionate to the pain they caused on earth.<sup>81</sup>

Therefore, the fact of sin cannot be a cause for despair. First, it does not diminish God’s love for us. Second, we need not be ashamed because Christ has taken upon himself all of the blame for our sin.<sup>82</sup> Third, because of the rightfulness of God’s creative work in the redemption, through Christ’s passion,

[there is] a great raising and fullness of bliss that mankind is come to,  
far surpassing what would have been ours had we never fallen.<sup>83</sup>

Despite the fact that sin exists, is painful, and remains as an inevitable part of our existence, Julian still believed that it is possible to experience hope. Hope results from Julian’s belief that Christ’s saving work makes even greater happiness possible, for

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<sup>78</sup> Denise Nowakowski Baker, *Julian of Norwich’s Showings*, 68.

<sup>79</sup> Julian of Norwich, *Revelation of Love*, chap.27, 55.

<sup>80</sup> *Ibid.*, chap. 52, 115.

<sup>81</sup> Julian described this understanding of the rewards of heaven in chap. 38 in *The Long Text*. The purpose of these rewards is “to make us glad and happy in love.” The theology provides a concrete example of the power of rightfulness of God’s creative work which matches evil and its attendant suffering with a corresponding and equal power for goodness and joy.

<sup>82</sup> *Ibid.*, chap. 51, 109.

<sup>83</sup> *Ibid.*, chap. 52, 115.

humans and God alike, than existed prior to the fall. The work of redemption more than compensates for the damaging effects of sin.

Julian's understanding of two-fold *anthropology*, expressed in her notion that humans are composed of substance and sensuality, also provided her with a basis for hope. Julian believed that

[I]n every soul that shall be saved is a godly will that never assents to sin and never shall. Moreover, this will is so good that it may never will evil but evermore and continually it wills good and works only good in the sight of God.<sup>84</sup>

Julian understood that this godly will is kept whole in Jesus -- it resides in our higher nature. Julian experienced both her awareness of this godly will and its role in drawing the lower part of the soul toward God in the eighth showing when she refused to look away from the cross. It was through this experience that she learned of the superiority of the inward part, the substance, over the sensuality. Further, she developed faith in the power of the substance to draw the sensuality by grace toward salvation.

Julian's understanding of the goodness of creation and the efficacy of Christ's redemptive work came together in her understanding of the *incarnation*. Julian's understanding of the incarnation provided her with a means for explaining how God works both in human creation and in redemption.

Julian argued that, in the incarnation, a necessary precondition for redemption, Jesus made possible the original union between substance and sensuality that characterized human nature in creation. In taking on human flesh, Jesus knit sensuality and substance together and, further, knit to him all those who shall be saved.

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<sup>84</sup> Ibid., chap. 53, 117.

[F]or in that same time that God knitted [Jesus Christ] to our body in the Maiden's womb he took our sensual soul. In this taking, having enclosed us within himself, he oned it to our substance and in his oneing became perfect man. For Christ, having knit to himself all those men and women that shall be saved, is the perfection of humankind.<sup>85</sup>

This wedding of our substance and sensuality in Christ, according to Julian, makes humanity the pinnacle of creation, whose nature most fully reflects the nature of God:

God is kind in his being, that is to say, that goodness that is kind [i.e., nature], it is God. He is the ground, he is the substance, he is the same thing as kindness and he is the true Father and very Mother of Kind. And all kinds he has made to flow out from him to work his will shall be restored and brought again into him by the salvation of humanity through the working of grace. For of all the kinds he has set partially in the great variety of creatures, only in humankind is it set whole and in its fullness, by virtue, beauty, goodness, in royalty and nobility, and in all manner of celebration of refinement and honor.<sup>86</sup>

Goodness in creation, therefore, resides in the *imago dei* borne by God's creatures, and the *imago dei* is most fully known in humankind because of the union in humans of substance and sensuality achieved through Christ.

The work of redemption, which Julian described as re-making, also requires the incarnation. Julian used the image of childbirth to describe this re-making, the redemptive act. She envisioned Christ's passion as labor and his death as childbirth, for in his death, he brings us to life.

Our own true Mother Jesus, he who is all love, bears us to joy and endless living – blessed may he be! Thus he sustains us within himself in love and labour until the full time when he gladly suffered the sharpest throes and most grievous pains that ever were or ever shall be, and died at last.

And when he had done, and so borne us to bliss, yet all this still could not satisfy his marvellous love. . . . And therefore he is compelled

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<sup>85</sup> Ibid., chap. 57, 127.

<sup>86</sup> Ibid., chap. 62, 139-40.

to feed us, for the precious love of his motherhood makes him a debtor to us.<sup>87</sup>

Julian's use of childbirth as a metaphor for the passion is reflected both in the form and content of her vision. The description of Christ's passage from death to life on the cross in the eighth showing parallels the movement from pain to celebration that accompanies the successful birth of a child. In the moment of birth, the arduous pains of labor fade and awe at the mystery of new life emerges. Julian captured the essence of this experience in her description of Christ's death and his consequent celebration of the fact that it has made life possible for those he loves. It is the vividness and aptness of this description that suggests to me that Julian herself may have experienced childbirth.<sup>88</sup> Further, I would argue that the notion of the Passion as childbirth is central to the development of Julian's theology; her theology grew from the image organically. The centrality of this metaphor shapes her unique development of maternal imagery for Christ.<sup>89</sup>

In Julian's view, redemption required the incarnation because in the maiden's womb,

our high God, who is sovereign wisdom of all, arrayed himself in this low

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<sup>87</sup> Ibid., chap. 60, 134.

<sup>88</sup> It is also possible, however, that Julian was drawing on the writing of other medieval theologians, including Anselm, who develop this same image. Jennifer Heimmel, for example, notes that Marguerite d'Oingt compares Christ's cross to a bed of labor and also speaks of his life and death in terms of a mother's labor. See Jennifer P. Heimmel, "*God Is Our Mother*": *Julian of Norwich and the Medieval Image of Christian Feminine Divinity*," *Salzburg Studies in English Literature* 92:5 (Salzburg, Austria: Institut für Anglistik und Amerikanistik Universität Salzburg, 1982), 27-29.

<sup>89</sup> This image may also have provided Julian with a means of finding meaning in suffering. Childbirth certainly requires much suffering, nevertheless, most often, it yields new life. I wonder if Julian may have used the metaphor as an interpretive framework for plague related suffering. Might she have asked what new life emerged from the pains of loss?

place, clothing himself in our poor flesh, so that he might himself perform the service and office of motherhood in all things.<sup>90</sup>

It was in the incarnation, therefore, that Christ assumed our sensuality, and according to Julian, it was this act that made possible Christ's suffering and death on our behalf. Just as humans are composed both of substance and sensuality, so was Christ, and it was Christ's sensuality, assumed in the maiden's womb, that suffered for humankind's salvation.<sup>91</sup>

Julian fully developed the image of Christ's motherhood to encompass the entire work of redemption. As Heimmel notes, one gets the impression upon reading the text that Julian has sought out earlier literary forms used to describe God as mother and integrated them all in her treatment of this theme. Her treatment of this metaphor does not just reiterate earlier works, however, for Julian developed and elaborated their imagery into a complete, connected cycle encompassing the entire passage from birth to death.

Julian's majestic vision proceeds through all the various stages of: enclosure and growth within the womb, the trauma of labor and birth, the suckling of the infant and the feeding of the child, the care and education of the older child, the setting of examples and the disciplining of the child, the washing, healing, forgiving, and comforting of the child as it matures and the continual loving, touching and guiding of the child even to the point of its own death which becomes in turn a rebirth and return to the original womb.<sup>92</sup>

In short, Julian used this metaphor to describe a loving God who desires our salvation and

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<sup>90</sup>Julian of Norwich, *Revelation of Love*., chap. 60, 133-34.

<sup>91</sup> Ibid., chap. 55, 123.

<sup>92</sup> Heimmel, "God is Our Mother," 54-55.

who accommodates to our needs at every stage of life to nurture us and bring us to fullness of life. Her development of this image provided a sharp contrast to the notion of a harsh and punishing God expressed during the plague. While Julian did not explicitly address God's role in disasters, her view of God's solicitous love seems contrary to the belief expressed by many in the plague that God abandoned humans and the earth as a result of sin. Julian's understanding of the incarnation and redemption united her belief in God's loving and rightful nature, thus providing a further basis for trust.

The final basis for trust that Julian provided is her reference to a deed of the Holy Trinity.

There is a deed which the blessed Trinity shall do on the last day, as I see it, and when that deed shall be and how it shall be done is not known to any creatures that are beneath Christ. . . . This is the great deed that God has ordained from without beginning, known only to himself, the deed by which he will make all things well.<sup>93</sup>

Julian believed that God has hidden this deed from us so that we shall be kept in peace. The context in which Julian revealed the deed suggests that it may be associated with universal salvation. Julian could not rest easily with the fact that many were to be damned. It was in the course of her reflection on this point that Christ revealed the deed and further indicated, even in light of the Church's seemingly contradictory teaching on this point, that he most definitely had the power to make all things well. Christ said:

What is impossible to you, is not impossible to me. I shall keep my word in all things, and I shall make all things well.<sup>94</sup>

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<sup>93</sup> Julian of Norwich, *Revelation of Love*, chap. 32, 63.

<sup>94</sup> *Ibid.*, chap. 32, 63.

Perhaps Julian herself may have profited most from the secrecy associated with the great deed! Since its nature was hidden, Julian was able to affirm God's loving nature revealed in her vision and the Church's stricter judgment. Further, she was freed from having to provide a concrete vision for how this seeming incompatibility might be resolved in the case of non-Christians and the lapsed.

In conclusion, Julian's theological synthesis provided a counterpoint to the prevailing theology of her day. It re-affirmed the goodness of God and creation and the efficacy of Divine Providence. Julian, who wrestled with the harmful effects of sin, came to realize that, although we may not keep ourselves from sin, we shall also not be punished for it. Instead, we shall be rewarded with joy for our repentance. Finally, Julian even hinted at the possibility of salvation for "heathen people" and Christians who have abandoned charity.<sup>95</sup> What undergirded her positive theological vision was the notion of a homely and courteous God who longs for our joy and salvation. Julian's encounter with God's unfailing love for her, expressed in her vision, provided the firm foundation for her affirmation that, indeed, all shall be well.

#### Julian's Spirituality

As indicated above, Julian's spirituality, based on her affirmation that "all shall be well," can be characterized as a spirituality of trust and longing. Julian's distinctive spirituality grew out of her experience of the loving God she encountered in her vision. In light of this experience and her reflection upon it, we shall now consider the manner of life Julian proposed for believers. What, in her view, made it possible for believers to

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<sup>95</sup> Ibid.



develop and maintain a relationship with the loving God she had come to know? What beliefs and practices enabled them to transcend day-to-day concerns, doubts, and limitations and live with the confidence that all shall be well? Addressing these questions is essential in developing an appreciation for Julian's spirituality. In our treatment of this topic, we shall attend to three aspects: first, Julian's understanding of the purpose of life and the human condition; second, the possibility of self-transcendence and the means to it; and, third, life informed by the knowledge that "all shall be well."

#### The Purpose of Life and the Human Condition

Julian's attempts to fathom the purpose of life were indelibly influenced by the fact of her vision. Given the life-changing effects of her revelation, this is certainly understandable, for Julian clearly came to a deeper knowledge of God, of herself, and of the meaning of life through her revelations.

In reflecting on the reality of her vision, Julian came to several conclusions. First, she realized that she had received her vision for the benefit of all Christians.<sup>96</sup> Second, she concluded that the revelation was made for several purposes. These included, first, that we might come to know God; second, that we might come to know ourselves; and third, that we might know ourselves as we are in our sin and feebleness.<sup>97</sup> A final reason for the revelation was that God wanted to give people light and solace with the

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<sup>96</sup> Ibid., chap. 8, 18.

<sup>97</sup> Ibid., chap. 72, 158.

contemplation of heavenly joy, so that they might experience relief from the sorrow and darkness of this life.<sup>98</sup>

The clearest effect of Julian's vision upon her theology and spirituality rests in the emphasis Julian places upon sight. Seeing becomes a central metaphor in her theology and spirituality, and her stress upon this notion is most directly reflected in her views regarding the purpose of life and the human condition. After receiving her revelation, Julian reached the conclusion that we were created for two ends: union with God and union within ourselves. In one particularly inspiring and expressive passage, Julian described the former union as a total sensory experience in which

[after death] we will be hidden in God without end, seeing him truly, feeling him fully, hearing him in spirit, and smelling him delectably and swallowing him sweetly.<sup>99</sup>

Yet, even here, Julian gave priority of place to vision. For, in the next breath, she stated that

we will see God face to face, homely and fully; the creature that is made shall see and behold God who is maker without end . . . .<sup>100</sup>

Perhaps inevitably, therefore, Julian, the visionary, expressed the ends of our existence in terms of sight: we shall achieve fulfillment and bliss when we have clear sight of God and clear sight of ourselves as God sees us.

And I know full well, when these two may be seen wisely and truly, we shall get rest and peace here, at least in part, and by his plentiful grace know its fulfillment in the bliss of heaven.<sup>101</sup>

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<sup>98</sup> Ibid., chap. 86, 181.

<sup>99</sup> Ibid., chap. 43, 86.

<sup>100</sup> Ibid., chap. 43, 86-87.

<sup>101</sup> Ibid., chap. 51, 103-04

With this clear vision will come the union of our will with God's will.<sup>102</sup>

In reflecting upon her vision, Julian concluded that the degree of sight she had experienced in it was extraordinary, indeed! She stated:

I knew in this showing of God that such a way of seeing him cannot be continuous in this life, by reason of his dignity and so that our endless joy may grow. And therefore we often fail in his sight, and presently we fall into ourselves.<sup>103</sup>

Julian believed, therefore, that the perfect sight of God that will bring us bliss, peace and rest is reserved for us in heaven.

Julian's choice of blindness as the central metaphor for the human condition followed directly from her understanding that we do not have clear sight of God in this life. She described our state of life as follows:

I understood that we are changeable in this life: overcome by frailty, we fall into sin. We lose all our strength, all common sense – also our will is overlaid; in these moments we feel nothing but tempest, sorrow and woe. And the cause of all this is blindness; we cannot see God. For if we were to see God continually, then there would be none of this mischief, nor any manner of stirring[,] that yearning to enslave us in sin.<sup>104</sup>

The human condition, therefore, is a condition of deprivation of the clear sight of God.

The consequence of this deprivation is that

we may never cease from mourning and weeping nor longing until the time we can see [God] clearly in his blissful countenance.<sup>105</sup>

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<sup>102</sup> Ibid., chap. 42, 82.

<sup>103</sup> Ibid., chap. 47, 93.

<sup>104</sup> Ibid.

<sup>105</sup> Ibid., chap. 72, 157.

Our blindness invariably leads us to sin, which is the cause of our pain. The inevitability of sin led Julian to characterize this life as a prison and penance, for she believed that whatever we do, we will have sorrow.<sup>106</sup> Nevertheless, as noted above, Julian believed that sin serves a useful purpose because it increases our knowledge of our human limitations, leading to meekness, and it increases our awareness of God's love. Julian prized the meekness resulting from knowledge of our sin, for in her view, it makes us like children, dependent on Mother Christ:

And I took it that in this life there is no higher state than childhood, that feebleness and failing both in capacity and understanding that shall last until such time as our gracious Mother has brought us back to our Father's bliss.<sup>107</sup>

Julian described the gracious way in which a courteous God reveals our sin to us creating this meekness, so that we may benefit from the self- knowledge we gain without losing heart.

For in his courtesy, he measures the sight for us, for indeed it is so vile and horrible that we could not endure to see it as it really is. And by this humble knowledge, through condition and grace, we shall be broken from all those things that are not our Lord; and then our blessed Saviour will heal us perfectly and make us one with him.<sup>108</sup>

The knowledge of our sin is mercifully tempered by God's goodness.

In her treatment of the effects of sin, Julian expressed a final helpful effect of it in her belief in the fruits of spiritual conflict. According to Julian, the conflicts between

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<sup>106</sup> Ibid., chap. 77, 168.

<sup>107</sup> Ibid., chap. 63, 142.

<sup>108</sup> Ibid., chap. 78, 170.

right and wrong that we encounter in this life increase our strength and our reward, “for if our faith has no conflict, it would deserve no reward.”<sup>109</sup>

When considering the human condition, therefore, Julian argued that human beings were created to achieve union with God in heart and will and, thereby, to appreciate their own goodness as created in God’s image. Attainment of this perfect union, however, is reserved for the life to come; for in the present world, humans are afflicted with blindness and frailty and fall inevitably into sin. Given these propensities one may rightly ask what factors, in Julian’s view, enabled us to move toward the union with God that we desire and that is our rightful end? The answer to this question resides in Julian’s two-fold understanding of self-transcendence to which we shall now turn.

#### Self-Transcendence and Its Achievement

If we accept Julian’s characterization of humans, as limited by sin yet destined for union with God, we must confront the question of how we are able to transcend our limitations and move toward the end for which we were created. According to Julian, the basis for self transcendence resided in the dynamic tension between trust and longing. That is, Julian believed that we must trust that God is present with us and one with us, even though we cannot see this. At the same time, we must seek God and behold God in everything as an expression of our longing for union with God. We must also seek the virtue of our higher nature, or substance, which draws our lower nature toward the integration God intends for us.

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<sup>109</sup> Ibid., chap. 70, 155.

The necessity for trust, of course, arises from our blindness. Because we do not see God face to face in this life, and because we also do not see ourselves as God sees us, we must learn to have faith in common sense, the teaching of the Church and the grace of the Holy Spirit working in our souls.<sup>110</sup> These three, operating in tandem, allow us to know of God and of our value as God's creatures. As Julian noted, all of these are gifts and "all work us to God."<sup>111</sup>

While we cannot see God face to face in this life, on the basis of her revelation, Julian stated that Christ wants us to trust

that he is with us all the while. For so he is in three ways: he is with us in heaven, true man drawing us up into his own person (and this was shown by his spiritual thirst); and he is with us too on earth leading us on (and this was shown in the third revelation where I saw God in a point); and he is with us within our own soul endlessly dwelling, ruling and caring for us (and this was shown in the sixteenth revelation, as I shall say.)<sup>112</sup>

Confidence in the latter point, that God dwells within our soul, allows us to have faith that we, like Julian, shall not be overcome. This confidence also enables us to trust in God's salvific work on our behalf. As Julian noted repeatedly, this work begins with the gift of our substance and ends with the perfection of our sensuality through the workings of mercy and grace. In her view, trusting also enables us to pass over our sufferings lightly because, in doing so, we express our faith that God will take us from

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<sup>110</sup> Ibid., chap. 80, 173. Note that these correspond to Julian's oft cited distinctions between nature, mercy and grace. Common sense resides in our nature, the church's teachings are an expression of Christ, and Christ's mercy and grace are the action of the Holy Spirit.

<sup>111</sup> Ibid.

<sup>112</sup> Ibid., chap. 52, 114.

our pain. According to Julian, God wants us to find comfort even in our death and in our passing. God showed Julian that you will have no more pain of any sort, no more discomfort, nothing

you will want, but all shall be joy and bliss without end. Why [then] should it seem hard for you to suffer awhile since that is [God's] will and does [God] honor?<sup>113</sup>

As I have already suggested, Julian postulated a dynamic tension between trust and longing. On the one hand, trust manifests our certainty that God is with us; on the other hand, our longing for God manifests our awareness that we do not yet fully possess union with God. Our longing for God is a mirror image of Christ's longing for us, which Julian described as Christ's spiritual thirst that will persist until all destined for salvation are united with him in heaven.<sup>114</sup> Julian noted that our seeking for God in this life is as good as finding God, for it is God's will that we seek God, and the act of seeking is itself an expression of trust.<sup>115</sup> In fact, Julian noted that the longing we have for God may also be understood as a form of penance, for it is with us throughout this life and never leaves us until we come to final union with God in heaven.<sup>116</sup> The principle value of longing, therefore, is that it draws us toward heaven. Our longing for God leads us so deeply into God that we come "verily and truly to know our own soul."<sup>117</sup>

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<sup>113</sup> Ibid., chap. 64, 143.

<sup>114</sup> Ibid., chap. 31, 61.

<sup>115</sup> Ibid., chap. 10, 24.

<sup>116</sup> Ibid., chap. 81, 176.

<sup>117</sup> Ibid., chap. 56, 124.

Julian described two main resources related to trust and longing that foster self transcendence. These included prayer and repentance. Prayer is valuable for two reasons: first, it provides a means by which we may experience union with God in this life.<sup>118</sup> Second, prayer helps to make our will supple to the will of God, that we may be joined to God in all things.<sup>119</sup> Prayer is a concrete expression both of longing and trust, for it arises “from a right understanding of the fullness of joy that is to come, as well as a longing and sure trust that it will be ours.”<sup>120</sup> Repentance, in contrast, arises from contrition, compassion and longing.

By contrition we are made clean, by compassion we are made ready, and by true longing for God we are made worthy. These three are the means by which, as I understand, all souls come to heaven; that is to say, those who have sinned on earth and shall yet be saved, for by these medicines it is fitting that every soul be healed.<sup>121</sup>

According to Julian, therefore, it is through prayer and repentance that we are able to express our trust in God’s love for us and realize the object of our longing, namely, union with God. These two activities provide powerful vehicles that enable us to overcome the limitations imposed by the human condition and to further our movement toward our ultimate destiny in God.

#### Living As If “All Shall Be Well”

In light of her identity as a survivor, it is fair to say that Julian’s view of life realistically captures its ambiguities and sorrows. Nevertheless, Julian concluded that,

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<sup>118</sup> Ibid., chap. 43, 85.

<sup>119</sup> Ibid., chap. 43, p. 86.

<sup>120</sup> Ibid., chap. 42, p. 84.

<sup>121</sup> Ibid., chap. 39, p. 76.



although this life is difficult, the most honour that we can pay to God comes as we live “gladly and merrily for love of him in our penance.”<sup>122</sup> Joy in this life is made possible because of God’s unfailing love for us, a love that “keeps [us] full surely.”<sup>123</sup> Despite the fact that we must fall, as Julian noted,

in falling and rising we are always preciousely kept in one love. For in the beholding of God we do not fall, in the beholding of ourselves we may not stand; and both these are true as I see it. But the beholding of God is the highest truth . . . .<sup>124</sup>

It is this truth that provides the basis for hope.

As noted above, perhaps the most remarkable effect of Julian’s revelation is the confidence it instilled within her in God’s loving nature. Through her vision, Julian came to understand that “we have been loved and known in [God’s] endless purpose without beginning”<sup>125</sup> and, further, that God’s love for us “was never slaked, nor never shall be.”<sup>126</sup>

In the final analysis, it is Julian’s recognition and appropriation of this love, concretely manifested in her vision, that is the source of her healing, confidence, and triumph over the fear of death. Her belief in God’s love and goodness produced a certain faith in the efficacy of God’s actions on our behalf. As she noted:

when the doom and judgment is given and we have all been brought up above, then we will see clearly in God those secret things that are hidden from us now. Then will none of us be stirred to say: ‘Lord,

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<sup>122</sup> Ibid., chap. 81, 175.

<sup>123</sup> Ibid., chap. 82, 177.

<sup>124</sup> Ibid.

<sup>125</sup> Ibid., chap. 85, 180.

<sup>126</sup> Ibid., chap. 86, 181.

if only it had been thus, then it had been full well'; but we shall say all with one voice: 'Lord, blessed may you be! For it is thus, it is well.'<sup>127</sup>

For Julian, love was the source of light, the foundation of goodness, and the basis for hope. According to Julian, it is God's unfailing love that insures that all shall be well, and her unshakeable confidence in this fact is her powerful and enduring legacy.

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<sup>127</sup> Ibid., chap. 85, 180.

## EPILOGUE PART II

### REFLECTIONS FROM HISTORY TOWARD EMANCIPATORY PRAXIS

Before proceeding to an exploration of AIDS loss in San Francisco, it seems both wise and desirable to reflect for a moment on the findings from our historical analysis with an eye towards integration with current experience. The purpose of this epilogue, therefore, is to spell out initial parallels between Julian's time and our own, to name certain possibilities that have arisen from our inquiry for understanding multiple loss, and to lift up problems, ways in which Julian's world view may limit application of her thought to the contemporary situation.

#### Parallels between Plague and AIDS Loss

Perhaps the most surprising findings at this point are the very real parallels that exist between the experience of multiple loss resulting from the Black Death in the fourteenth century and the experience of multiple loss from various causes, including AIDS, in the twentieth century. A number of these spring immediately to mind. The first includes the abandonment of the sick and dying that was so prominent a feature of the chroniclers' account of the plague. This, too, is characteristic of the response to AIDS, and was particularly prevalent in the early days when the disease was little understood, as this account from a gay San Francisco survivor suggests.

The critical personal point was that my spouse . . . became ill and died very quickly. That really changed my perspective on the epidemic and of the gay community. There was so little support . . . . The phobia was so thick that you could just cut it with a knife. Most of our friends disappeared or just never came to the hospital. . . . We were kids and we didn't expect that this was going to be part of our lives.<sup>1</sup>

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<sup>1</sup> G'Dali Braverman, interview, in *White Nights and Ascending Shadows: An Oral History of the San Francisco AIDS Epidemic*, ed. Benjamin Heim Shepard (London: Cassell, 1997), 84.

Fear in the face of poorly understood illness seems striking in both contexts.

Another significant parallel may be found in the growth of apathy in the wake of multiple loss. In the words of a San Francisco AIDS survivor:

Grief has become an ongoing thing for me. You become numb. Sometimes you feel like you can't go to another memorial.<sup>2</sup>

Both fear and numbing resulted from the sheer numbers of deaths in the early days of the AIDS and plague pandemics, as well as from the terrible fear of contagion associated with each of these maladies.

In addition, as we have already seen, the stigmatization and violence toward the marginalized that accompany epidemics has been no stranger to persons with AIDS.

While this has sometimes been expressed in outright physical violence against gays or ostracism of the infected, the violence often is expressed more subtly. In 1983,

Newsweek reported that

besides politicians using AIDS to justify antisodomy laws in Texas and Georgia, gay people had been told to leave restaurants, refused ambulance service, and evicted from their apartments simply because they were perceived as having AIDS.<sup>3</sup>

Violence can take many forms, including enforced isolation, stigmatization, economic deprivation and outright neglect. A prominent feature of the fourteenth century context in the case of the Flagellants was that violence against self appeared to be correlated with violence against others. In other words, the presence of one form of violence may have been associated with others. This raises questions about the extent to which the

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<sup>2</sup> Raoul Thomas, interview. Ibid., 107.

<sup>3</sup> Andriote, *Victory Deferred*, 69.

emotionally and physically violent climate of homophobia in the United States contributed to the minimization of AIDS and also to the limitation of resources to address its devastation. This surely was a form of passive, as opposed to active violence, though the consequences of this passive form of violence were no less severe. The ACT-UP slogan "Silence=Death" verifies this reality.<sup>4</sup>

Fear of outsiders, so prominent a feature in accounts of the Black Death, is also part of the landscape of AIDS, as Nord notes.

AIDS is the quintessential disease of 'otherness.' . . . the foreignization of AIDS occurs on an explicit and implicit level. Explicitly, foreigners are blamed for AIDS . . . It is common practice in nearly all nations to bar visitors and immigrants who test positive for AIDS. Foreign culprits are blamed for AIDS throughout the world, consistently viewed as harbingers of the virus, although who exactly is considered foreign differs.<sup>5</sup>

Perhaps the most significant parallel, however, is the tendency to invoke God's punishment as a justification for illness and death, particularly when medical explanations are lacking. As we have already noted, in the United States, this response characterized leaders of the religious right, such as Pat Buchanan and Jerry Falwell, who viewed the infection of gay men as divine retribution. While there is a tendency for liberal Christians to distance themselves from these more extreme spokespersons, the lack of tolerance for, and full inclusion of, gay and lesbians within many Christian churches today speaks to a

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<sup>4</sup> ACT-UP, an AIDS activist organization, was founded by Larry Kramer who also was instrumental in forming Gay Men's Health Crisis in New York. ACT-UP was formed in the Spring of 1987 to raise the visibility of the AIDS epidemic and, in particular, to agitate for drug research and to improve access to treatments. ACT-UP is now an international organization. The organization promotes the use of "guerrilla tactics" to achieve its aims. See Elinor Burkett's account of the history of ACT-UP in *The Gravest Show on Earth: America in the Age of AIDS* (New York: Picador USA, 1995), especially chap. 12.

<sup>5</sup> Nord, *Multiple AIDS-Related Loss*, 23.

continuing suspicion of difference, the same psychological dynamic that underlies the more extreme views of the religious right.

The striking nature of these parallels suggests important similarities between the psychological response to multiple loss in Julian's time and our own. As striking as they are, however, rather than assuming that the responses are identical and disclose universal psychological patterns, we shall continue to search for cultural nuancing of the experience of multiple loss as we move into a fuller description of the contemporary experience of AIDS loss in San Francisco.

### **Possibilities for Healing**

Three significant insights have emerged from our exploration of Julian's religious and psychological response to multiple loss. First, Julian's vision illustrates the creative way in which the religious imagination may rework traditional religious content in the service of healing. Through her vision, Julian appropriated the symbol of the crucifixion as a tremendous aid in overcoming the death imprint, death anxiety and survivor guilt. Her appropriation of this symbol was wholistic and integrated: she drew on the symbol's sensory qualities as well as upon its theological interpretation.

A second insight emerging from Julian's experience is that healing may result when individuals re-experience the painful feelings associated with trauma within the context of symbolic meaning and community support. While Julian drew on her earlier experience of loss in responding to the crucifixion, she was able to re-interpret the cross. Her vision of the crucifixion, while painful, enabled her to move beyond the emotionally crippling aspects of her earlier experiences with death. Further, the presence and

response of the Christian community at hand provided her with the support she needed to accept and integrate this profound religious experience.<sup>6</sup>

Third, Julian's experience suggests that greater self-acceptance and acceptance of others may be a fruit of healing from the trauma of loss. Julian repeatedly mentions the importance of unity with her fellow Christians and the necessity of looking beyond others' sins. This is the perspective of a healed survivor: Julian came to view herself as no more or less guilty or worthy than others, thus opening herself up to the possibility of full communion with others. As we have already indicated, Julian's reflections on eschatology suggest that she may also have been open to communion with non-Christians and lapsed Christians as well.

### **Problematic Aspects of Julian's Theology**

Julian's theological synthesis constitutes an important resource to survivors of massive death. Her view of God's loving nature, her positive characterization of the human will, and her notion that God does not blame us for our sins are key aspects of her witness that provide reassurance to believers. In addition, Julian's use of the motherhood of Christ as a resource in understanding God's work in redemption helps to make her understanding of God's love both concrete and compelling.

Other aspects of her understanding, however, pose some problems, particularly in light of contemporary theological developments. Julian's notions of sin and suffering emphasize the personal, as opposed to the corporate nature, of these realities. In my

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<sup>6</sup> In chaps. 2 and 21 of the Short Text and in chaps. 3 and 66 of the Long Text, Julian describes the presence of other Christians, including her curate, at her bedside. The fact that a priest took her revelations seriously when she was inclined to doubt them was a source of shame and sadness to her. These emotions were dissipated with the final revelations that night.

view, this limits her theology, particularly in light of liberation theologies which have convincingly demonstrated the power of systemic forces in contributing to human disease and pain. For example, issues of oppression have contributed greatly to the suffering of persons living with AIDS in the twentieth century. Julian's theology does not appear well-equipped to embrace the effects of oppression. She appears to interpret all suffering as participation in Christ's suffering and finds redemption in establishing this connection. However, she does not question how oppression may, in fact, have caused the suffering Jesus experienced, nor does she address ways in which confronting unjust societal oppression may alleviate unnecessary suffering.

Second, Julian offers an other-worldly understanding of eschatology, in which human happiness and fulfillment await satisfaction in the life of the world to come. On the one hand, Julian is to be commended for her willingness to wait patiently for God to make all things well and to abandon unresolvable curiosity about when and how that shall take place. On the other hand, it does seem as though Christians, participating as co-creators with the Divine, may contribute to improving the world here and now. While Julian does advocate that we live joyfully in the present, at times she appears to emphasize the pain and suffering of this life. Perhaps a lack of enthusiasm for the present life remains as a vestige of her life as a survivor.

Finally, Julian appears to adhere to a satisfaction theory of the atonement in which Christ takes on the sins of humankind as a surrogate. This raises several key questions, as Dolores Williams has so helpfully pointed out in her treatment of the atonement. Satisfaction theories of the atonement introduce a tension within God with regard to why a loving God would require a painful sacrifice to effect salvation. Further, they place an



emphasis on suffering as salvific, as both liberation and feminist theologians have noted.<sup>7</sup> Finally, they situate the grounds for salvation in Christ's suffering and death rather than in his healing and life-giving ministry. While Julian's views are certainly advanced for her day, they do raise important questions in light of contemporary theological understandings, questions that we shall address at a later point.

Keeping in mind the parallels, possibilities and problems raised by our historical analysis, let us now turn to a description of All Saints and its theology and spirituality to gain further insight into the reality of AIDS loss and its effects.

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<sup>7</sup> These two helpful points are made by Eugene Teselle in "Atonement," *A New Handbook of Christian Theology*, ed. Donald W. Musser and Joseph L. Price (Nashville: Abingdon Press, 1992), 43.

### **Part III**

#### **Descriptive Practical Theology**

## CHAPTER 7

### “DYING IS WHAT THE LOVING DO”: THE EFFECTS OF AIDS LOSS ON ALL SAINTS CHURCH

. . . And what cats have to tell  
on each return from hell  
is this: that dying is what the living do  
that dying is what the loving do,  
and that dead dogs are those who never know  
that dying, is what, to live, each has to do.<sup>1</sup>

All of us are here . . . because we have in some way been crucified  
and raised with Christ, because when we have been dead God has  
been with us, and because in every kind of death God's resurrection  
power has raised us.

And we're here because we trust that God will continue to do that for us  
and for all people.

It's as simple as that really, and as various and as personal: new life, over  
and over again. . . .

Life, as in eternal life, resurrection life, not “fix everything, looking good,  
happy-ever-after life” but life that comes to us when we descend into the  
depths of death and find God there with us, present with a presence and  
loving us with a love that cannot be broken by anything.<sup>2</sup>

As I noted in Chapter 1, I experienced my most intense encounter with AIDS  
while I worked as a chaplain at San Francisco General Hospital in 1990-91. That

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<sup>1</sup> Alastair Reid, “Curiosity,” in *The Poetical Cat: An Anthology*, ed. Felicity Bast (New York: Farrar, Straus & Giroux, 1995), 144.

<sup>2</sup> Susan J. Singer, sermon preached at All Saints Episcopal Church, San Francisco, 9 April 2000, obtained from preacher. Singer is a pastoral associate at All Saints and also serves as the Director of Education in the Diocese of California.

experience left me both frustrated and curious. I was frustrated with the individualistic model of pastoral care I experienced, and I was curious about the potential for a congregational-based AIDS ministry. In an attempt to explore the potential for congregational involvement in AIDS ministry, I spent nearly a year in 1991-2 as a field education student and deacon at Grace Cathedral in San Francisco. At that time, Grace was bringing a variety of resources to bear on the AIDS epidemic in San Francisco, including sacramental, educational, spiritual and pastoral ministries. I was impressed then and remain impressed now with the Cathedral's willingness to take a public stand for compassion and to minister with care to those living with HIV/AIDS and surviving AIDS losses. Through its annual AIDS Day of Remembrance, its regular provision of anointing for healing and bereavement groups, its buddy program and the institution of the AIDS memorial chapel, Grace has managed over the years to keep issues of HIV/AIDS in the forefront in San Francisco.

My journey was to take me from San Francisco at the end of that year; however, my curiosity about the effects of HIV/AIDS on congregational life remained undiminished. Thus, when I had the opportunity to return to the Bay Area in 1995, I began to think again about how to assess the effects of AIDS on the life of a congregation. The current study represents the outcome of this process of questioning and exploration. Let us now turn to an exploration of the methods and findings of the ethnographic study of a San Francisco congregation heavily affected by HIV/AIDS.

### **Rationale for the Present Work**

As I noted in Chapter 1, there are three principle reasons for choosing to study the effects of AIDS on a congregation as a whole. First, congregational study provides a window through which to observe the process of communal bereavement, since AIDS tends to affect entire communities. Second, my pastoral experience with AIDS and AIDS loss generated an interest in systemic models of pastoral care. Studying the ministry of a congregation provides a means of exploring the pastoral ministry of a community as a whole, rather than focusing on the ministry of individual caregivers. Third, studying the ministry of an entire congregation seemed most appropriate to the development of an emancipatory praxis of care. The congregation provides a laboratory for the study of praxis, as the congregation is a place both of action and reflection; further, in the normal course of events, these two “moments” of care are highly integrated within a church’s life. For all of these reasons, then, the study of a congregation appeared to be desirable and promised to be fruitful.

The main research question guiding this portion of the study is: What effect did multiple AIDS loss have on the life, ministry and theology of a congregation? The descriptive and analytical work undertaken in this research was directed toward this question. In this chapter, we shall focus on the methods of study used to address this question and on the preliminary results they yielded. In the next chapter, we shall explore the theological and spiritual effects of AIDS loss upon the church in greater depth.

### **The Choice of the Congregation and the Methods of Study**

A number of Episcopal congregations in San Francisco suffered severe losses from AIDS from the mid-1980s to mid-1990s. However, after visiting several of them

and after discussing the options with The Rt. Rev. William Swing, the Episcopal Bishop of California, I decided to study All Saints Episcopal Church. All Saints is a pastoral congregation located in the Haight-Ashbury district of San Francisco.<sup>3</sup> Three features of this congregation, in particular, influenced my decision to study it. First, the pastoral leadership of this church has been rather stable: in the last 21 years the congregation has been served by only two rectors with a one year interim between them. Further, the congregation has been blessed with stable and well-developed lay leadership. Second, the current rector, Kenneth L. Schmidt, who served during the period of greatest loss came to All Saints with a Ph.D. in theology and superior skills for preaching and reflecting on the pastoral crisis facing the congregation. In addition, I knew through preliminary conversations that Father Schmidt shared my interest in AIDS loss.<sup>4</sup> In fact, he has been engaged for several years in writing a book on the psalms of lament as a pastoral resource in congregational bereavement. Thus, I anticipated that he would be a thoughtful reflection partner. Finally, while All Saints has a fair percentage of gay and lesbian members, it has never been identified as a primarily gay parish in the way that one or two other city parishes have been. Thus, I anticipated the availability of a more diverse congregation than I might have found in some other Episcopal churches sustaining significant AIDS loss.

After I shared my interest in studying All Saints, Father Schmidt provided encouragement and an invitation to discuss my intentions with the Vestry of the parish. I

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<sup>3</sup> See Appendix II for information about attendance at All Saints.

<sup>4</sup> The reference to All Saints' rectors as "Father" is consistent with the Anglo-Catholic tradition that has characterized the parish's worship life since the mid-1950s.

formally met with the Vestry on October 12, 1998 and they expressed their willingness to allow me to proceed with this research.

My interest in focusing on the congregation as the unit of study encouraged me to draw on approaches to congregational study developed by James Hopewell, Denham Grierson, and Nancy Ammerman and her colleagues.<sup>5</sup> Each of these approaches has its own particular strengths, however; what is common to each of them is the use of a variety of methods for “taking the pulse” of a church community

In my approach to the study of communal bereavement, I have relied, in particular, on several methods. First, for over one year, I engaged in the worship and fellowship of All Saints as a participant observer. I hoped through these efforts to understand better the distinctive “culture” of All Saints. Second, I conducted 14 semi-structured interviews with both clergy and laity affiliated with the congregation. The primary purpose of these interviews was to elicit information about the individual experience of bereavement. Third, I conducted a survey of a random sample of the congregation to allow me to describe accurately certain demographic and attitudinal characteristics of the church’s members. Fourth, I studied important documents in the life of the church, including the parochial reports and annual reports from the mid-1980s

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<sup>5</sup> For information about congregational study approaches, see James F. Hopewell, *Congregations: Stories and Structures* (Philadelphia: Fortress, 1987); Denham Grierson, *Transforming a People of God* (Melbourne: Joint Board of Christian Education of Australia and New Zealand, 1984); Nancy T. Ammerman, Jackson W. Carroll, Carl S. Dudley, and William McKinney, *Studying Congregations: A New Handbook* (Nashville: Abingdon, 1998).

to the present.<sup>6</sup> I also interviewed the parish archivist about the history of the parish. The purpose of this study was to enhance my appreciation of historical developments in the life of the parish. Finally, I held one group interview to examine specifically the communal aspects of bereavement at All Saints and the interaction of the individual and communal experiences of bereavement.

In analyzing my field notes and interview transcripts, I relied on the grounded theory method of Barney Glaser and Anselm Strauss.<sup>7</sup> I used this method because I was interested in developing an inductive theory about AIDS loss and its effects on a congregation, and the method is well-suited to this aim. In my analysis, both the field notes and interview transcripts were subjected to open coding, axial coding and selective coding. In open coding, the written records, namely the field notes and interview transcripts, were analyzed line by line for their conceptual content. In axial coding these concepts were grouped into categories and related to one another by means of the paradigm model described by Strauss and Corbin.<sup>8</sup> Finally, in selective coding, I chose a core category, and I developed a descriptive analysis about the central phenomenon to

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<sup>6</sup> Parochial reports are required annually by the denomination and the diocese and they provide information about membership, attendance at key services, programs and the parish financial situation. Annual reports, in contrast, are produced yearly by the members themselves for the annual meeting of the parish. They contain the rector's "state of the parish" address, financial and stewardship information, and written reports from lay leaders associated with the parish's programs.

<sup>7</sup> See Appendix I on the grounded theory method. See also Barney G. Glaser and Anselm L. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Chicago: Aldine, 1967); and Anselm Strauss and Juliet Corbin, *Basics of Qualitative Research: Grounded Theory, Procedures and Techniques* (Newbury Park, Calif.: Sage Publications, 1990). I relied heavily on the latter source.

<sup>8</sup> Strauss and Corbin, *Basics of Qualitative Research*, chap.7, 96-115.



which it pertained. The results of these analyses of the field notes, the individual interview and group interview transcripts will be summarized below.

### **A Brief History of All Saints<sup>9</sup>**

The first service of the congregation to become known as All Saints was held on the Feast of All Saints, November 1, 1903. However, planning for this event began at least 5 years earlier in 1898, when The Rev. Edgar Lyons, Rector of the now defunct St. Stephen's Episcopal Church on Fulton Street in San Francisco, proposed the establishment of a mission in the Haight. Thus, he began a Sunday school in a kindergarten on Hayes Street. With Lyon's death in 1903, oversight of the Sunday school was transferred to St. Luke's Episcopal Church. On October 12, 1903, The Rev. E. W. Hayes, Assisting Priest at St. Luke's who was later to become All Saints' first rector, held an organizational meeting for All Saints. The outcome of this meeting was the first Sunday service, described above, held in the parlor of a cottage on Haight Street.

Following these modest beginnings, the parishioners of All Saints gathered the money to build a new church fairly quickly -- they raised the building and had their first service in the church on Easter Sunday, March 1, 1904. At that time, the church building was located at 1205 Masonic Street. The church, which was built in 30 days, cost \$2,500, while the land on which it rested was worth \$5,000. Roughly 220 people attended the first service. The church quickly moved from mission status to parish status: it became a

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<sup>9</sup> I am indebted to Lawrence Holbein, parish archivist, who generously shared with me the results of his research into the All Saints Parish Archives. Holbein is currently working on an account of the parish history in anticipation of the parish's 100<sup>th</sup> anniversary in 2003. Further information was obtained in a telephone interview I conducted on July 5, 2000 with Elizabeth Pepin at KQED, the public television station in San Francisco. Pepin began research on the Haight in preparation for a series on San Francisco neighborhoods being developed by KQED.

parish on September 23, 1905. On that occasion, All Saints had about 90 communicants and there were 125 children in the Sunday school. One of the highlights in the early years occurred in October of 1905 when the church was moved from its location on Masonic Street to its current location in the middle of a city block on Waller Street between Ashbury and Masonic Streets. Apparently, the noise of trolley cars traveling up and down Masonic Street obscured the music and preaching – thus, parishioners made the decision to move the building!

While the information in the parish archives is uneven, two trends seem prominent in the history of All Saints. The first is the way in which the demographics and the health of the parish parallel trends in the neighborhood. When All Saints was founded, the neighborhood around it was called “Asbury Heights,” and it was a fashionable, upper- class neighborhood attracting as residents politicians and a new generation of mercantile wealth. In the first period, the neighborhood residents were largely Caucasian. This trend continued until after World War II. At that time, with the pressure of development to the East, the African American population in the Fillmore was displaced and more and more African Americans began moving into the Haight. Beginning in the late 1940s and early 1950s, then, the neighborhood and the parish became more racially and demographically diverse. San Francisco State University, located close by into the early 1950s, tended to attract a younger population to the Haight. The proximity of the college and the increased availability of cheaper housing in the Haight made it easier for the young to live there than in other parts of the city. The availability of reasonably priced housing in the early 1960s also encouraged an influx of “bohemians” from the North Beach area, and thus the seeds were sown for the “Summer

of Love” of 1967 and the massive invasion of the young into the Haight-Ashbury neighborhood in the late 1960s. Following the “Summer of Love,” the neighborhood was literally inundated with young people. A housing shortage soon followed, and with the turn toward hard drugs, the neighborhood became a riskier place in which to live and do business. Beginning in the late 1960s, then, the neighborhood experienced a period of decline in which many businesses closed and property values plummeted.

The hard times the Haight experienced in the 1960s continued well into the 1970s, until the economy began to turn around in the late 1970s with the development of an alternative music scene. The Haight, which had grown increasingly tolerant over the years of alternative lifestyles, became a center for the development of the punk rock movement. That same period began to witness rising prosperity in the city, and people once again began to buy and develop real estate in the Haight-Ashbury district. The growing prosperity of the region continued into the 1980s and the 1990s. Today, the Haight, like many neighborhoods in San Francisco, is becoming home to single young professionals. These new residents are benefiting from the new prosperity accompanying the rise of the “dot com” culture flourishing in the greater Bay Area. However, the neighborhood’s history of bohemianism and tolerance is still reflected in its colorful and creative inhabitants. Further, the presence of young, homeless, and addicted residents, many of whom sleep nightly on the neighborhood’s streets, are reminders of the shadow side of the Haight’s culture.

As indicated above, trends in the parish closely followed trends in the neighborhood. Early in its history, the members of All Saints tended to be upper middle class Anglophilic Caucasians. After World War II, the church attracted a growing

number of African American families as well as some Pacific Islander and Latino families, and the members tended to be more solidly middle class. Like most churches in the 1950s, All Saints had a healthy population of families and children and a thriving Sunday school. However, a crucial turning point for All Saints occurred in the 1960s. In the face of the influx of the young into the Haight, the rector of All Saints, Leon Harris, made a decision to minister actively to the young people. He was of the opinion that the Church is not a private club that exists to make its members comfortable. With his blessing, All Saints became the center of activities for a social group known as the Diggers. The Diggers emerged early in the hippie movement, and they engaged in an assortment of political and social service activities using All Saints as a headquarters. They cooked meals in the All Saints kitchen and served them on the streets of the neighborhood and they provided free clothing which they stored in the undercroft of the parish. They also provided drug counseling. At the same time, they hosted many meetings and discussions in the parish facilities.

Over time, because of the presence of the Diggers and the hospitality of Father Harris, some of the young people inhabiting the Haight began to make their way into the church for Sunday services. Simultaneously, the parish experienced significant theft and destruction of property. Apparently, many of the older members of the parish were not happy with these occurrences, and the late 1960s witnessed an exodus of All Saints' members from the parish. This loss of members was the first of two notable and painful losses that All Saints was to experience; the second, associated with AIDS, was to begin nearly twenty years later.

We have already noted that the 1970s were low years for the Haight – at the same time, they were difficult years for All Saints. Father Harris, who had been acclaimed as the “patron saint of Haight Ashbury” in the late 1960s, retired in 1971 after a 22 year pastorate. Only a handful of parishioners remained at All Saints after the turmoil of the 1960s, and the parish was served in the 1970s by a series of rectors. None of these priests succeeded in reversing the downward trends in attendance the parish was experiencing. Indeed, in some cases, their actions only heightened the disruption of the community. One rector, for example, apparently disenchanted with the movement toward the ordination of women in the Episcopal Church, attempted to convince the congregation to become Roman Catholic. This attempt did not sit well with the members of the congregation, and more importantly, it was not well received by the Bishop who ultimately deposed him.

The low point for All Saints came in 1979, when the Bishop of California began to contemplate closing the parish. However, at that time, a forward thinking layman, Neil Little, who was active on Diocesan Council, resisted this move. In his opinion, the Haight-Ashbury was too strategic a location to be abandoned by the Episcopal Church; further, he appreciated the aesthetic appeal of the church building and did not want to see it experience further decline. Therefore, Mr. Little took it upon himself to lobby for the survival of All Saints and, until his death in 1993, he poured his money, evangelistic skill and considerable energy into spearheading a renaissance of the parish. Mr. Little, who was an openly gay man, invited many of his gay and lesbian friends to All Saints. He also supported the administrative and pastoral efforts of The Rev. Lloyd Prator, who became rector in 1979. Their combined leadership resulted in a rebirth of All Saints. Father

Prator, who is a gay priest, ministered effectively both to the parish's growing gay and lesbian population and to its faithful long-time members. The presence of the strong pastoral leadership of gay men is undoubtedly the most important factor that prepared All Saints to welcome and to minister to the many HIV-positive gay men who found their way to the parish with the advent of AIDS. However, the hospitality extended by all the members of the parish, including the church's African American matrons, was also an important factor in the church's renewal.

Unfortunately, Father Prator's partner was diagnosed with AIDS in the late 1980s, and this factor, among others, led to Father Prator's resignation and move to New York City. This move was followed by a one year interim, and this interim period led to the flowering and consolidation of strong lay leadership within the parish. The cultivation of this leadership was deliberately fostered by the interim, The Rev. Rollie Jones. During the interim period, the search committee actively sought a pastor who would be equal to the pastoral challenges that both the congregation and community were experiencing with the continued heightening of the AIDS epidemic in San Francisco's gay community. Further, they looked specifically for a priest who would understand the social and personal challenges faced by the parish's gay and lesbian members during these difficult years. These criteria led to the hiring of Kenneth Schmidt, and he began his pastorate at All Saints in April of 1989.

In summary, the character of the church appeared, on the whole, to reflect the character of the Haight, and years when the Haight thrived seemed to be associated with prosperity in the church. A second significant trend that emerges from the history of the parish is the church's long involvement in ministry to its neighbors. For example,

following the 1906 earthquake, the undercroft of All Saints served as an emergency hospital and relief station. In the teens, the Asbury Heights Women's Guild, a powerful women's suffrage group, met at All Saints. One of All Saints' most successful rectors, Arthur J. Child, who presided at the Church in the 1930s, was hailed by the press upon his death for his promotion of civic good. In the late 1950s, Father Harris deliberately adopted an Anglo-Catholic worship style in an attempt to reach out to the newer residents of the Haight. We have already described the church's involvement with the young people in the Haight in the 1960s. The archives attest to the fact that outreach ministry continued into the 1970s in a free breakfast program for young children run by the church. Further, All Saints has sponsored a Saturday brunch program for its homeless and hungry neighbors in the Haight for many years. In the late 1980s and early 1990s, the church sponsored a support group for HIV-positive individuals. Finally, a number of twelve step groups regularly use the church as a meeting place. Since its beginnings, therefore, All Saints has been concerned with the welfare of her neighbors. Maintaining outreach programs in a small church is not easy; but the members have placed a high priority on outreach over the years and have drawn upon resources from other Episcopal churches, when possible, to supplement their efforts.

### **Results of the Demographic and Attitudinal Survey**

Before turning to more detailed analysis of the effects of AIDS on All Saints, it may be helpful to describe briefly the characteristics and attitudes of the current members of All Saints.

A few facts may help to put the survey results in perspective. Currently, the average Sunday attendance at All Saints is 90 members. There are roughly 140 active

members and the total budget is about \$200,000. Close to 100 individuals and households pledge. The members worship in an Anglo-Catholic style and they value the arts. Earlier, they contributed generously to refurbish the parish organ, and they have successfully attracted top quality organists and choir directors. The parish also continues actively to support a feeding program for its neighbors in the Haight, sponsoring a brunch on Saturday mornings. Further, an above average number of parishioners and associate clergy serve in significant leadership roles in Diocesan affairs.

To obtain a thumbnail sketch of the parishioners and their views, I administered a survey to a random sample of All Saints' current members. I adapted the survey from a form developed for the study of congregations by Nancy Ammerman and her associates at Hartford Seminary – the adapted form, along with a summary of the overall results, may be found in Appendix III.<sup>10</sup>

I drew my sample from names listed in the parish directory. To obtain a random sample, every 5<sup>th</sup> parishioner out of roughly 134 listed was chosen to receive the survey. This yielded a sample of 25. I mailed a survey and cover letter to the entire sample, and obtained responses from 20 people. Two of the original 25 members sampled stated that they no longer considered themselves members of All Saints. I was unable to contact 3 of the 25. Fifteen individuals returned the surveys to me directly – I contacted the remaining 5 and, with their help, I completed the survey over the telephone. Thus, the rate of return was very high, and we can have good confidence that the reported results are indeed representative of the congregation's current members.

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<sup>10</sup> Ammerman's survey may be found in her book, *Congregation and Community* (New Brunswick: Rutgers University Press, 1997), 377-80.



My survey of the congregation indicated that the average parishioner has been attending All Saints for 12.58 years. The range of years of attendance varied from 3 to 43 years, and the median years of attendance was 6. This result suggests the presence of a number of longer term members, but a higher proportion of newer members. Further, of the twenty members responding, thirteen reported prior affiliation with a denomination other than the Episcopal Church.

The most frequent activities engaged in by the members of my sample at All Saints were worship services and choir. Further, the members appear to value highly personal prayer and meditation as a form of spiritual practice; 45% of the sample reported engaging in personal prayer and meditation on a daily basis.

Members regularly attending All Saints most often come alone. Forty-five percent of those who consider themselves regular attenders (9/12 members) report that they come to church by themselves. Only fifteen percent of the sample comes from households with at least two regular attenders. Further, nearly 70% of those in the sample state that none of their five closest friends attends All Saints. From these data, one can conclude that All Saints' members come to church because they are personally motivated to do so, not to meet close friends or to worship with family. This finding reflects the relatively high proportion of members who live alone: 45% of the total sample.

Members live fairly close to the church. On the average, it takes them about twenty minutes to travel to Church. Further, many have resided in their current communities for some time, as the average length of residence was 19.25 years. In

addition, All Saints' members tend to be highly educated. Sixty percent of the sample are either college graduates or hold post-graduate degrees. Further, 55 percent of the sample report household incomes in excess of \$50,000 per year.<sup>11</sup> Fifty-five percent of the members surveyed also report holding either professional or managerial occupations, a finding consistent with the educational and income trends reported above.

The congregation is somewhat diverse: sixty-five percent of the members trace their heritage to Europe, while the remaining percentage of members, on the whole, have a mixed ethnic and racial heritage.

Members' views on the Bible are rather liberal: only two members of the twenty respondents believe in Biblical inerrancy. Forty percent of the members do subscribe to the belief that the Bible is the Word of God, whereas the greatest percentage (45%) view the Bible as "a record of many peoples' experience with God [and] a useful guide for individual Christians in their search for basic moral and religious teachings."<sup>12</sup>

When they consider the qualities of a good Christian life, members appear to prize most highly spending time in prayer and meditation and practicing Christian values in home, work and school. Seventy percent of the sample ranked time spent in private prayer as essential and another 20% considered it very important. Second, 55% ranked

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<sup>11</sup> Yet only 20% report pledging \$2400 per year or more to the congregation – 35% of the sample pledges between \$100 and 599 per year, while 20% pledges between \$600 and 1199 per year. However, that being said, I should also note that the members of All Saints are the most generous I have seen in an Episcopal Church; besides pledging, many members regularly make special gifts of various kinds, including giving for building upkeep and improvement, altar flowers, bread and wine, and most recently, for the construction of a columbarium.

<sup>12</sup> Compare these results with the catechism in *The Book of Common Prayer* which describes the Holy Scriptures as "the Word of God because God inspired their human authors, and because God still speaks to us through the Bible," in "An Outline of the Faith, commonly called the Catechism," in *The Book of Common Prayer* (New York: Church Hymnal Corporation, 1979), 853.

the practice of Christian values as essential, while an additional 35% considered it very important. The quality ranked third, caring for the sick and needy, was an activity considered essential by 45% of the congregation and very important by an additional 35% of the members sampled. Members ranked these activities above others, such as attending church regularly, reading and studying the Bible regularly and seeking to bring others to faith in Christ.

When the members were queried about All Saints' activities in the community, they ranked fostering an appreciation of diversity in the church and world first. Fifty percent of members viewed this as essential, and another 35% ranked it as very important. The second most highly ranked community activity is helping members as individuals to be good citizens while the third most important activity is cooperation with other religious groups for community improvement.<sup>13</sup>

Finally, when asked about their images for God, members tend to describe God in "functional" terms such as Comforter, Liberator, Savior or Creator rather than in terms of the parental images, Father or Mother.

When considering the overall results, two especially interesting findings emerged, and I examined them at greater length. First, a fairly high proportion of the total sample could be described as infrequent attenders, as 35% of the sample reported attending church less than once a month. Second, nearly half the sample reported attending All

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<sup>13</sup> Here it is important to note that the parish has actively engaged in partnerships with other Church groups in recent years. These included a partnership with the neighboring Roman Catholic Church in the feeding program and, most recently, a parish partnership arrangement with nearby St. Cyprian's Church, a predominantly African American Episcopal Church. The latter has regularly shared clergy, worship and fellowship with All Saints over the last four years. However, moves toward a more substantial partnership are somewhat in abeyance at present due to leadership transitions at St. Cyprian's.

Saints for less than 6 years. Therefore, I looked specifically at the contrasts between more frequent and less frequent attenders and newer and older members.

The results of these analyses indicated that, in comparison with those who have been members longer, newer members tend to pledge more and are more likely to view the Bible as the word of God. In addition they attend church much more frequently. Older members, in contrast, tend to have lived nearly 6 years longer in their communities, are more educated, and tend to make more money. Further, they also tend to be more ethnically diverse.

Turning to the contrast between frequent and less frequent attenders, it appears that members who attend more frequently pledge more. They are more likely to describe the Bible as the word of God.<sup>14</sup> They are more likely to live alone. Further, they tend to be more educated and wealthier than less frequent attenders and they are more likely to be of European descent. On virtually every other indicator, there appear to be few significant differences among members. That is, they tend to rank the qualities of a Christian life, community activities and images of God in a remarkably similar way.

In what ways might the trends we describe reflect the effect of AIDS upon All Saints? First, the emphasis on personal prayer and meditation may be viewed for a good number of members as a fruit of their experience of traumatic loss. Evidence for this conclusion comes from the interview findings where members repeatedly spoke of how the experience of AIDS loss had deepened their spirituality and that of the parish.

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<sup>14</sup> These parallels between newer members and more frequent attenders also reflect the fact that many more newer members attend All Saints frequently.

Second, the fact that many members worship alone may reflect, at least in part, some ambivalence within the gay and lesbian community toward religious institutions. A fair number of those who worship alone are partnered gay men and lesbians whose partners do not choose to worship with them. However I think it is also possible to understand the church culture as a “single” culture as opposed to a “couples” culture, as there are relatively few married couples at All Saints. This trend does appear to be slowly changing in recent years.

Third, the priority members place upon practicing Christian values and being good citizens may reflect a vigilant attitude which they have adopted as more “marginal” members of society. Such attitudes *may* be viewed as the fruit of oppression, an experience that was heightened for many by AIDS. Several of the preferred images for God -- as savior, liberator and deliverer -- may also be considered as fruits of oppression. On the whole the members of All Saints are not drawn from groups that can afford to be complacent politically -- this hard lesson was reinforced in both the civil rights movement and the early days of AIDS. Members of All Saints are thus concerned with issues of public life and actively seek to integrate theological views with political and social understandings.

Fourth, the emphasis on appreciating diversity that is important to members may reflect the societal marginalization that many members of All Saints’ experience. However, it may also be a consequence of traumatic loss and the stigmatization associated with AIDS. That is, as All Saints gay and lesbian members experienced stigmatization because of their sexual orientation, particularly in the early days of the

epidemic, they may have become much more committed to fostering a societal appreciation of difference.

Finally, the high priority members place on caring for the sick and needy surely reflects their communal experience of HIV/AIDS.

Having considered the character of All Saints' members as a whole, let us now explore more closely the effects of AIDS loss upon the congregation.

### **The Magnitude of AIDS Loss at All Saints**

Examination of the burial register at All Saints indicates that the parish was involved with the funeral and/or burial of 34 men from March 23, 1983 through 1997. The average age of the men for whom this information was available was 38.7 years, and the range was 24-55 years. However, these figures do not tell the whole story, as other parishioners and men associated with the parish who were living with AIDS either left the parish to return to their families to die or had their funerals elsewhere. Further, since four major hospitals are located within the parish boundaries, including Davies Medical Center and the University of California Medical Center, both parishioners and clergy were frequently called upon to minister to others living and dying with AIDS. Figure 3 illustrates the total number of AIDS and HIV-related deaths by years, as listed in the parish's burial register. Figure 4 illustrates the number of deaths from all causes listed in the All Saints burial register from 1978 to 1999.

As examination of the data indicates, 1993 was the year in which All Saints sustained the greatest number of AIDS losses. In February of 1993 alone, the parish performed three funerals. Besides the significant number of AIDS deaths in 1993, All Saints also lost Neil Little to cancer in March of that year. Mr. Little's death was

Figure 3

AIDS and HIV-Related Deaths Per Year

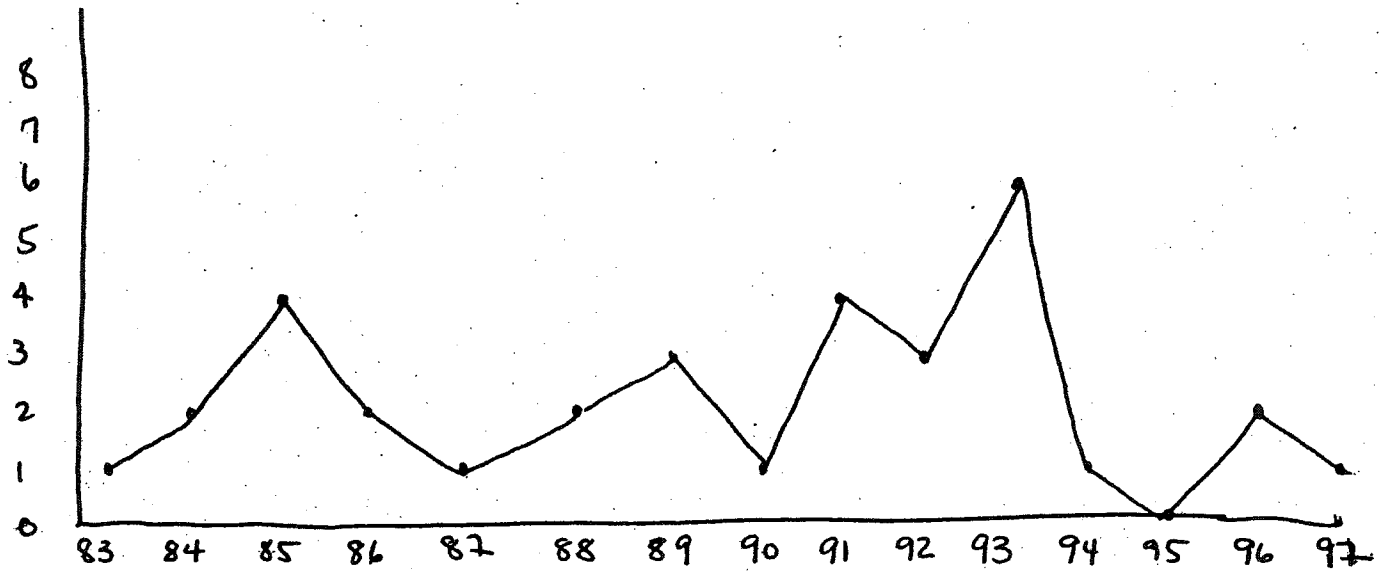
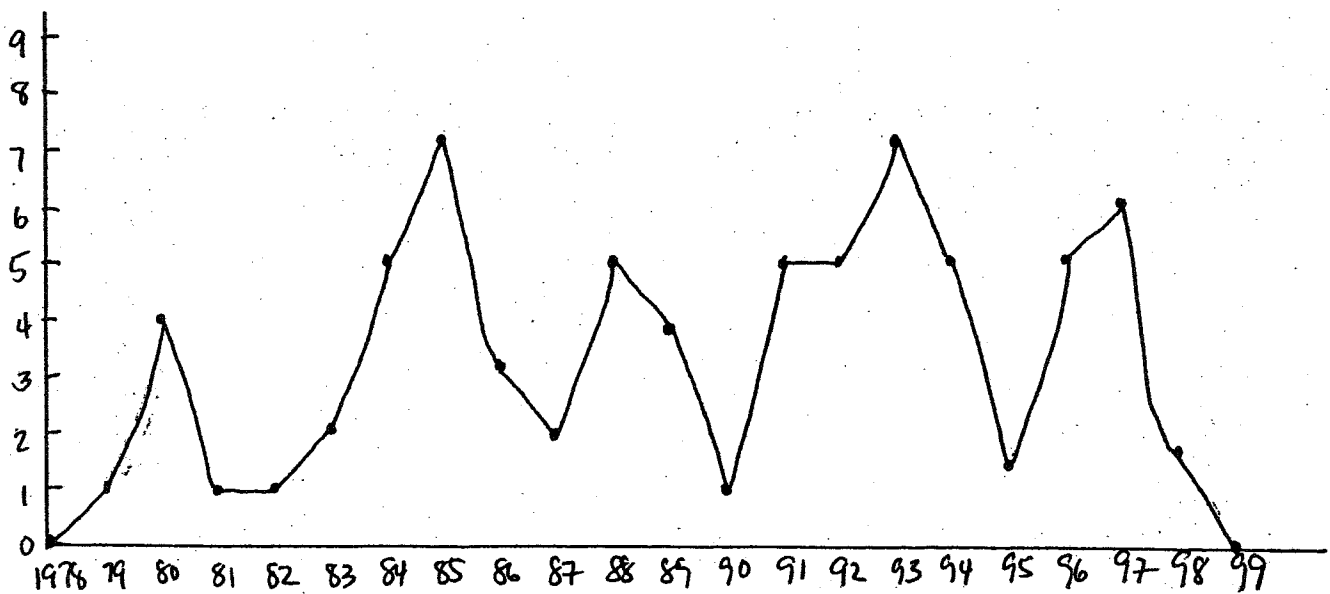


Figure 4

Number of Deaths by All Causes Per Year



experienced by the parish as an overshadowing loss, despite the fact that it was not HIV-related.<sup>15</sup> This is because Mr. Little was a figure of great importance to the parish and his death created an emotional void in members. Two other deaths were also experienced as overshadowing by the parish: the first AIDS death of a parishioner on January 29, 1985 and the death of an extraordinarily well-loved parish leader on June 14, 1990.<sup>16</sup>

### **Effects of Loss on Individual Parishioners**

As one aspect of my attempt to explore the effects of AIDS loss on the members and clergy of All Saints, I conducted a series of semi-structured interviews in the Fall of 1999. In all, I interviewed three clergy and eleven lay members of the parish. All interviews began with two open-ended questions designed to elicit the parishioners' experience of AIDS and AIDS loss and its relationship to their participation at All Saints. These questions were first, Could you tell me the story of your experience with AIDS and AIDS loss?; and second, How have these influenced your participation at All Saints? Following those, interview questions focused on four major topics: the parishioner's

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<sup>15</sup> The term "overshadowing death" was first used, to my knowledge, by Gregory Neil Shrader in his dissertation on multiple AIDS loss. He used it to refer to one significant death that seemed to overshadow all the other losses a survivor experienced. In his view, this death was usually the same death that had the biggest impact upon the survivor: a lover, a close friend, or the first AIDS loss. In other cases, the 'overshadowing death' was either someone with whom the survivor had had an ambivalent or conflictual relationship, someone who did not let the survivor know that they were dying or someone who did not include the survivor in their death process. He notes: "the 'overshadowing death' contributed to many survivors' feeling that they were never completely able to feel resolved over their loss for this significant person." See Shrader, "Descriptive Study of the Effects of Continuous Multiple AIDS-Related Losses," 87. An interesting finding of the present study is that communities, as well as individuals, appear to experience certain deaths as overshadowing.

<sup>16</sup> The first AIDS funeral at All Saints did not result from the death of parishioners, but from people in the community whose families came to All Saints for their funerals. Other early funerals were of people who came to the parish as they were dying. The death of the first active parishioner, which came two years after the first AIDS funeral, was an extraordinarily significant and emotional event for those I interviewed, in part because the death occurred so quickly and because it broke through parishioners' denial, suggesting that they, also, could contract AIDS.



experience with AIDS and HIV disease, the nature of AIDS loss and grief, the effects of loss on their theology and spirituality, and the effects of AIDS losses on other aspects of their lives, including their relationships, sexuality, and views about death.<sup>17</sup> Most interviews took between two and three hours – most were conducted in the parishioners' homes and the remainder took place at the church, with the exception of one interview held at the researcher's home. One parishioner volunteered to be interviewed – a few others were solicited from the researcher's knowledge of them, but most were solicited through referrals from previously interviewed parishioners. Interviews were tape recorded and a complete transcript was typed for each.

In all, I interviewed a total of 4 lay women, 7 lay men and 3 clergy.<sup>18</sup> Of the lay subjects, 64 percent described themselves as gay or lesbian, while 36 percent identified themselves as heterosexual. Their length of membership at All Saints averaged 17.7 years, and ranged from 4 to 41 years. Parishioners and clergy in this study sustained an average acquaintance loss to AIDS of 61.5 people. In addition, they had lost an average of 8.8 close friends and partners to AIDS. Losses in the acquaintance category ranged from 5 to 200, while losses in the close friend and partner category ranged from zero to 30. Thus, it is immediately evident that losses in the parish represented only the tip of the iceberg for many of the parishioners at All Saints. One parishioner, who lived for a significant period of time in the Castro, reported the loss of virtually his entire generation to AIDS. This became particularly evident to him at a recent street fair when he noticed

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<sup>17</sup> The interview protocol for the individual interviews may be found in Appendix IV.

<sup>18</sup> A summary of the demographic characteristics of the interviewees may be found in Appendix V. This data does not include information from two interviewees who failed to return their questionnaires.

how few men his age were present. This same parishioner commented on the comprehensiveness of loss: he lost two barbers, his dermatologist, half of a musical group to which he belonged, many members of a twelve step group he attended, and countless store clerks and neighborhood “fixtures.” In summary, the members of this parish experienced considerable AIDS loss both within and outside their church community with the greatest bulk of the losses occurring between 1985 and 1993.

### Analysis of the Interview Results

#### Grounded Theory Analysis

As noted above, analysis of the interview data proceeded according to the grounded theory method described by Anselm Strauss and Juliet Corbin. Interviews were audiotaped and transcribed, and in the open coding phase the transcripts were coded line by line according to their conceptual content. Following this microanalysis, the concepts were grouped into categories. Sixteen categories emerged in this first phase of the analysis and they provide an overview of the interview contents. Interviewees talked about their early experiences with HIV/AIDS, the gay lifestyle, the meaning, diagnosis and management of AIDS, and AIDS deaths. Other categories included the psychological effects of AIDS loss, the effects of AIDS loss on religious beliefs and practices and on the parishioner’s spirituality, and the number, nature and uniqueness of AIDS losses. Additional categories included reflections on overshadowing losses, the process of grieving AIDS losses, coping strategies, and feelings associated with AIDS and AIDS loss. Interviewees also addressed the nature of their relationships with persons living with AIDS. Finally, interviewees reflected on the history of All Saints and upon the parish’s AIDS ministry.

In the next phase of the analysis, I attempted to describe the relationship between these concepts and categories. In doing so, I reached a preliminary understanding of the perplexing situation faced by All Saints parishioners in the face of AIDS. The data, taken as a whole, seem to describe the way in which the people at All Saints came to live with the enormous degree of loss they experienced. Several key questions confronted them: How could they cope with both the loss of members and other losses associated with AIDS so that they and their community were not destroyed by them? How could they be faithful to the Gospel mandate to care without literally dying in the process or losing their faith? What strategies could they adopt for managing both their perceived risk of infection and grief that were sustainable and true to their Christian beliefs? In other words, how could they attempt to balance their need for safety and stability with the Gospel mandate to lose their lives for the sake of the Gospel?

Faithful engagement with persons living with AIDS and AIDS loss seemed to be a function of these parishioners' perceived vulnerability to loss. That is, parishioners who were at greatest risk of experiencing significant loss were more likely to engage less actively with the sick and infected. This perceived vulnerability varied as a result of two things: first, certain characteristics of loss that I have named "loss intensifiers" and second, parishioner susceptibility. Examination of Table 1 will help to clarify the nature of these two categories. Loss intensifiers include dimensions of loss that mediate the intensity of the experience of loss: they include such qualities as the closeness of the loved one who is dying, the number of previous losses sustained, and whether or not one has had an opportunity to achieve closure with the loved one who is dying.

**Table 1**  
**Factors Mediating Choice of Coping Strategy**

Hypotheses: A parishioner's perceived vulnerability to traumatic AIDS loss and to persons with AIDS varies as a function of two factors. These are described as 1.) loss intensifiers and 2.) parishioner susceptibility factors to infection and loss.

A parishioner's perceived vulnerability to loss appears to affect the choice of coping strategy. However, certain filters may mediate perception of vulnerability to loss and influence coping strategy, since not all persons at greatest risk tend to withdraw from engagement. Hypotheses regarding the nature of these filters, drawn from reflections on the interviews, are described below.

Subjects with more varied strategies may be more able to engage with the sick and infected.

Loss intensifiers

early experience with AIDS loss  
closeness of loved one who is dying  
number of prior losses sustained  
degree of stigma surrounding loss  
degree of closure with dying person  
age of deceased  
degree of suffering involved in disease  
rapidity of death  
degree of judgment of those with AIDS  
perceived potential of the deceased  
availability of effective treatments

Parishioner susceptibility factors

gay v. straight  
male v. female  
HIV+ v. HIV -  
being of a certain generation  
African American v. Caucasian  
lay v. ordained  
newcomer v. old timer  
leader v. peripheral member  
being in good health v.  
experiencing health crisis  
newly diagnosed v. long term  
survivor  
involved in arts v. non-involved in  
arts

Filters

emotional resilience  
personality style  
clarity of belief  
faith, i.e., ability to tolerate ambiguity  
capacity for compassion  
availability of emotional support  
certain emotions: ambivalence, guilt, anger, stress  
loneliness, fear, helplessness, worry

Parishioner susceptibility, on the other hand, refers to characteristics of the parishioners that influence the amount and nature of loss that they experience. So, for example, one could argue that a gay man of a certain age (a person of high susceptibility) who had sustained many previous losses and was facing the loss of a close friend (high intensity of loss) would have a heightened perception of vulnerability to loss. The combination of these two factors influenced the parishioner's adoption of a particular strategy for coping with loss, however, the adoption of particular strategies was not always easy to predict.

Strategies for faithful engagement were of several kinds. See Table 2 for a description of these strategies. Analysis of the interview data suggests that parishioners at All Saints tended to adopt varying strategies over time and many adopted more than one. In general, however, parishioners tended to move toward a "protecting" strategy as their experience of loss increased. Adoption of this style became necessary to prevent parishioners from being overwhelmed by the experience of AIDS loss. However, even after experiencing intense loss, parishioners were able to adopt the more active "caring" style, for example, when facing the death of a close friend. Interestingly, however, two of the interviewees with the greatest number of losses were exceptions to the move toward a "protecting" strategy: one, an HIV positive parishioner, continues to adopt an activist stance despite having experienced massive loss. It would appear that he has "made peace" with the presence of HIV disease and has been able to transcend the risk of both death and loss. The second exception may be understood as having the most

**Table 2**  
**Strategies for Coping with Loss and Outcomes**

<u>Protecting</u>	<u>Some Associated Outcomes</u>
developing a healthy routine	"safety"
being in a committed relationship	reduced risk of infection
limiting friendship circle	isolation
opting for comfort, stability, peace	depression
attempting to reduce infection risk	yearning
becoming proactive around my health	guilt
setting boundaries	unresolved grief
withdrawing from sick	
becoming sober	
 <u>Doing/Caring</u>	
engaging those who are ill	empowerment
ministering to ill, dying	burnout
keeping busy	
becoming an activist/volunteering	
protecting the sick	
persevering in caring	
 <u>Reflecting</u>	
"theologizing" about grief	understanding
asking why v. avoiding why questions	crisis of faith
learning about loss	
facing the painful reality of loss	
 <u>Transcending</u>	
praying	acceptance
getting outside of oneself	
becoming "small"	
engaging in spiritual quest	
 <u>Expressing</u>	
facing/expressing/plumbing my feelings	understanding
intensifying relationships	release
remembering the departed	
attending funerals	
seeking closure with dying	

varied repertoire of styles for he actively combined “caring,” “reflecting” and “transcending.”

Reflection on these cases suggests that it is possible to hypothesize the presence of certain filters that may mediate the choice of style(s) one adopts as well as the effectiveness of the style(s) once adopted. These filters include such important intangibles as the capacity for emotional resilience, clarity of belief, faith defined as the ability to tolerate ambiguity, personality style, capacity for compassion and the parishioner’s access to emotional support.<sup>19</sup>

Outcomes of the coping styles varied: clearly, the “protecting” style would appear to result in decreased vulnerability to loss. At the same time, however, it appeared to be associated for some parishioners with guilt, depression, and, in at least one case, with a yearning for meaning. “Caring” often seemed to provide a sense of empowerment. The one interviewee who clearly exemplified a “transcending” style expressed gratitude for his experiences of loss. He also noted that he sometimes felt guilty because he knew that while he had grown as a person, his growth had come about through the loss of many loved ones. The parishioner who most clearly used an “expressing” style did so in the service of emotional release and increased understanding. Of the three parishioners who used a reflecting style, two achieved increased understanding, while the third appeared to have launched himself on a spiritual quest that is taking him beyond the confines of the

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<sup>19</sup> The effectiveness of the style depends upon whether it results in greater self acceptance and self-transcendence, qualities associated with AIDS spirituality. While the “protecting” style did serve to limit a person’s contact with the sick and infected, many who adopted it were uneasy about the way in which it narrowed their range of vision and made them more self, as opposed to other, focused. It is important to remember, as Lifton reminds us, that survivors make many uneasy tradeoffs in situations of trauma that they would never accept in other circumstances and that these tradeoffs are simply part of the experience of surviving traumatic loss.

parish and its Episcopal theology and rites. Currently, this parishioner is actively exploring Native American and other non-Christian spiritualities.

### Narrative Analyses

In addition to the grounded theory analysis, two additional narrative analyses were performed on the data from the individual interviews. The first analysis examined interviewees' responses to the open-ended question which began the interviews. Each interviewee was asked at the start: "Could you tell me the story of your experience of AIDS and AIDS losses?" and was told, "I am particularly interested in discovering how these have influenced your participation at All Saints." The interview transcripts revealed that members of All Saints were using these questions as a way of talking about an overshadowing loss they had experienced to AIDS. In some cases, this loss was the loss of a particular person who was most significant to the parishioner, however, this was not always the case.

The results of the interviewees' responses to the open-ended questions suggest that the interviewees used this question as an opportunity to discuss three types of losses. Some interviewees used it as a chance to describe their first loss to AIDS. Others used it as an opportunity to talk about the loss of a person to whom they or the parish were closest. Finally, others used it as a chance to describe other significant losses besides the loss of people that either they or All Saints had experienced. For example, one HIV-positive interviewee spoke about his loss of health. Other losses mentioned included the loss of livelihood one member had experience through an important death, the loss of faith in the church another had experienced, the loss of the ability to grieve, the loss of other church members through transfer resulting from a historical conflict in the parish,



the loss of a sense of security about health and sexuality and, finally, the loss of a long term relationship that an interviewee had experienced that was only indirectly associated with AIDS.

The range of subjects treated suggests three things: first, *an individual's overshadowing AIDS loss may NOT be the loss of a person, but may be the loss of any one of a number of things, such as those mentioned above.* Second, the range of overshadowing losses described above serves only to accentuate the understanding of AIDS loss as a form of multiple loss, since its effects were so widespread in the lives of parishioners. Third, these findings also highlight the cumulative nature of loss, since, in some cases, questions about AIDS losses provided parishioners with an opportunity to talk about other significant losses.

The second narrative analysis focused specifically on the actual death narratives shared by interviewees. That is, an examination was made of the stories of specific deaths that interviewees had witnessed and which they described through the course of the interviews. These narratives were inspected to determine what features appeared to be both important and common to them. The results of the analysis indicated that the stories told by lay members of the parish differed from the stories told by the parish clergy.

Twenty-nine death narratives were shared by 10 lay people. In general, these stories focused either on difficulties the interviewees had experienced in grieving, *or* they focused on grief with a positive outcome. The most prominent difficulty mentioned by interviewees was an inability to gain closure with the dying. Five of the 29 stories shared focused on this concern. In one case, a particular subject told a series of stories about deaths he had witnessed and of a progression in his experience. He told these stories in

the course of a chronological account of his experience with AIDS and AIDS loss. In the first three stories he shared, he had been unable to achieve satisfactory closure with a dying friend; however, in the fourth story he shared, he did succeed in achieving satisfactory closure with his friend. This sequence shows a progression in this individual's ability to seek out and achieve closure with his loved ones who were dying, as he realized the emotional toll he experienced when he did not achieve closure.

Another interviewee shared three death narratives all focused on the issue of closure.

One story described the death of a person with whom she had neither a close relationship nor closure. The second story featured the death of a person to whom she was close, but with whom she lacked closure. The third story described the loss of a very close friend with whom she had achieved closure. This interviewee strongly believed that the "best" deaths and the most satisfactory grieving process could be achieved in situations where she was close to the deceased *and* where she experienced closure with the deceased prior to his or her death. In her experience, one of the greatest sources of pain at All Saints during the AIDS epidemic was the frustration she experienced in seeing people whom she did not know well die. She experienced a sense of helplessness and of thwarted potential in these situations.

Other stories described other difficulties that complicated the grieving process. These included such factors as the cost of caring for the dying, the sense of helplessness an interviewee felt in witnessing death, the pain accompanying a prolonged death, the sense of communal loss and shock associated with an All Saints' death, the struggle for authenticity in the dying process and an ethical quandary experienced with a dying friend.

Finally, two of the stories could be described as “it could be me” stories: stories in which individuals shared their similarities with those who had died.

Positive stories shared by interviewees could be described as stories of friendship, “salvation” and closure. One of the friendship stories commended the caregiving provided by two friends to a third, whereas the other described an interviewee’s participation both at the bedside and memorial service of a beloved friend. One of the “salvation” stories described the complete progression of a friend’s illness from diagnosis, to illness, to death to funeral to a sense of contact the interviewee had with that friend after death. The other described the church’s ministry to a young man’s family in the morning of his death and a “providential” occurrence related to it. In summary, then, stories told by lay members of the church appeared to focus either on positive or negative outcomes associated with death and dying, with a strong focus on either achieved or incomplete closure.

In contrast, stories told by clergy tended to be more mixed. In general they had both positive and negative elements. In addition, they tended to be about dilemmas the priests experienced in providing care and the grace associated with overcoming them. I examined 10 death narratives shared by my three clergy interviewees. Of these narratives, four stories focused on ethical quandaries associated with ministering to the dying. Three of these described ministry to end-stage AIDS patients contemplating or attempting suicide. Two stories focused on the stigma associated with an AIDS diagnosis and its effect on the family members of the deceased. Two stories described pastoral dilemmas associated with establishing boundaries in pastoral care. One story was a

“cautionary tale” about honesty for pastors working with the dying. Two stories were about transcending boundaries. Finally, one story was about facilitating a “good death.”

Analysis of clergy death narratives led to the conclusion that pastors who work with parishioners dying with AIDS are sometimes called to go beyond “conventional” boundaries in this ministry. That is, there are times when they may be asked to make difficult choices, such as how to minister to a parishioner who is planning to take his or her own life when the pastor does not approve of this plan. I was impressed over and over again with how the clergy I interviewed chose to act in a spirit of love rather than in a spirit of judgment and with full respect for the freedom of their parishioners in difficult situations. I was also impressed with the ability of clergy to transcend “normal” boundaries of care in the service of love when working with the dying. Ministry as death approaches may be exceptional in the way it heightens opportunities both for transcending boundaries and sharing God’s love. Clergy who are working with the dying, rather than simply symbolizing God and God’s love, may become free to incarnate that love in very profound ways.<sup>20</sup>

When considering the results of the individual interviews, therefore, the following results seem most significant. First, members of All Saints experienced profound losses to AIDS and these losses may be understood as multiple losses. Second, some losses

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<sup>20</sup> The psychiatrist, K.R. Eissler, in his book, *The Psychiatrist and the Dying Patient* (New York: International Universities Press, 1955), 197 describes the way in which the psychiatrist must also transcend normal methods of care when treating the dying. He speaks specifically about the notion of transference, and suggests that when working with the dying, transference, rather than being a means to an end, becomes an end in itself. Specifically, he states: “In these moments [when death approaches] the separation between external reality and internal reality crumbles, and the psychiatrist is no longer an object of transference; that which serves in the treatment of the living as a tool to help the patient back to life becomes here an end in itself, without a purpose beyond.”

were overshadowing, both for individuals and for the community as a whole. Third, not all members experienced equal loss – some had greater vulnerability. Fourth, the style of responding to loss differed, in part, as a function of parishioner vulnerability to loss. Finally, some important differences characterized the lay and clergy responses to losses at All Saints. Lay members attended more to issues of closure, whereas clergy engaged issues of ethics and boundaries in pastoral care.

### **The Effects of AIDS Loss on the Congregation as a Whole**

Two forms of data seemed most useful in assessing the effects of AIDS loss upon the congregation as a whole. The first is the data obtained from the participant observation research; the second is data obtained from the group interviews. Each of these methods yielded a different “story” about the effects of AIDS upon the congregation. I shall report each of them in turn and summarize their joint findings in this chapter – in the next chapter, I shall discuss the theological and spiritual content of these findings in greater depth.

#### **Analysis of the Field Notes**

The purpose of this section is to describe findings from the analysis of field notes that arose from participant observation of the congregation. These notes, drawn from worship services and fellowship occasions, provided important data about the congregation’s theology gleaned from sermons. Further, they helped to highlight aspects of the congregation’s life that were of great importance to the members. They also provide an entree into the communal experience of the congregation, in contrast to the interviews, which were focused to a much greater extent on the individual experience of loss.

As indicated above, the period of participant observation lasted for over a year. Although I began attending All Saints in September of 1997, I did not begin attending regularly or recording field notes until Holy Week of 1998. The first field notes describe the experience of the evening Eucharist on Monday of Holy Week, April 6, 1998. The last set of field notes is an account of observations of the Annual Meeting of the Parish held on Sunday, March 14, 1999. Field notes were recorded on 34 separate occasions. The vast majority of field notes describe Sunday services. However, other notes describe fellowship events, such as stewardship dinners, the parish retreat and the celebration for Father Schmidt's tenth anniversary at All Saints.

Analysis of the field notes yielded 99 concepts which were grouped into 10 different categories. The names of these categories provide an overall summary of the content of the field notes. The categories are: resurrection life, communion of saints/remembrance, hospitality, inclusion, ministry, interpersonal relationships, worship participation, vulnerability, the sacredness/transcendence of worship and the immanence of God.

The application of the paradigm model developed by Anselm Strauss and Juliet Corbin yielded a narrative summary of the data and the relationships between the categories. That is, the field notes describe how a congregation of people who have experienced marginalization to outright rejection in the world *and* traumatic loss encounter an imminent and incarnate God in the midst of this pain and are transformed through the encounter. In their encounter with the Divine, the congregation experiences resurrection life. Prerequisites for the experience of resurrection life include a willingness to be vulnerable, to face death and to be surprised by God. Resurrection life

requires courage and forgiveness. Further, resurrection life is experienced in the context of suffering, worship and relationship.<sup>21</sup> Having experienced resurrection life, the people of All Saints value justice, which may be understood as the extension of this life to all. The consequence of experiencing resurrection life is a desire for sharing the inclusive love of God, which is the basis for justice. At All Saints, the embrace of God's love is shared with those who are perceived as being on the margins, including gays and lesbians, the homeless and hungry, children and youth, the sick, women, persons of color, animals and even the parish's beloved dead, with whom members understand themselves to be connected in the light of God's love. Strategies for sharing God's love include, first, participation in worship, for worship creates the context in which the encounter with God takes place and in which the unity of the communion of saints is realized. A second strategy is engaging in ministry, which is understood to be about reconciling and creating unity, and a third strategy is offering hospitality. At All Saints, the extent to which members offer others a place at the table is understood to reflect the extent to which the members themselves enter the reign of God.

The main phenomenon at the heart of the parish's experience, therefore, is the experience of resurrection life. Resurrection life may be understood as the presence of God amid pain, suffering and loss. Parishioners have learned that there is no experience, however painful or difficult, that is outside of the province of God's love, whether the experience of being marginalized or the experience of AIDS loss.

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<sup>21</sup> These three arenas provide the congregation members with opportunities for self-transcendence. Thus, they will be important to our later discussion of the spirituality of All Saints.

The narrative summary of the field notes parallels one of the most important pastoral experiences in which Father Schmidt participated early in his time at All Saints. Both personal interviews and the group interview reveal that the death of Stephen Wilson was the death that had the greatest significance for the parish as a whole.<sup>22</sup> Stephen Wilson, who died at age 34 in 1990, was an outstanding parish leader. Besides serving as Senior Warden in Father Schmidt's first year at All Saints, Stephen was active in the food program and the church school. He was a very generous pledger. From all accounts he was handsome and witty, warm and friendly, and much loved by all the parishioners. In short, he was a man whose mark was felt in every area of the parish's life. To tell the story of AIDS loss at All Saints is to tell of the life and death of Stephen Wilson, for the experience of his death was at the center of the parish's experience of AIDS loss.

In ministering to Stephen in the week of his death, Father Schmidt describes his "conversion to love." His practice was to check in with Stephen from time to time to see if he needed any pastoral support, as his health was declining. Most of the time, Stephen did not "need a whole lot of care," but then:

Schmidt: finally, I did get a call from him, one Monday. I get choked up about it (he begins to cry), and since he'd never asked for help before, I knew he needed it. And, uh, I called Lucinda up [another parishioner scheduled to assist] because there was Mass, of course, . . . and Lucinda's words were, "For God's sake, just go. I'll do Evening Prayer." Which was very important, as it were, because it gave me permission to do what I did. So I went and that was my week. Not that I was there all week, but he died that Thursday. So, he went from being passably well to dead in that short time.

And that visit was one of the strangest visits . . . but it was one of the most wonderful visits, too, because it's the night that . . . was in a way a real personal conversion for me and it's a story I tell every now and again

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<sup>22</sup> The name, Stephen Wilson, is a pseudonym. I have chosen it to protect the privacy of this beloved member and his family.



to the congregation because there's such turnover in the congregation . . . But I tell it because I think, well, it's part of the history of the place, but . . . it's just an example of how conversion happens in very different ways and also happens in great pain. It's not overtly a conversion to God, it's a conversion to authenticity or in a way to yourself, but it's a transcendent conversion, it's transcendent because it's conversion to God whether you see yourself as already converted to God or not.

I: Is it a kind of conversion to faith, to a deeper level of trust?

Schmidt: Well, in this case to love, conversion to love. And . . . I was put in . . . just tremendous awkwardness. First of all, Stephen being Stephen, and being as popular as he was, he had too many people flocking around him that night. What he wanted to do was finally do his will and burial and he wanted to get that signed and wanted me there to witness it. . . . [Schmidt goes on to describe how, as they talked, Stephen's sister, a massage therapist, began massaging him and began undoing his shirt and collar and he describes his discomfort in that moment] So, suddenly I'm getting undressed and there, you know, you've got all this pastoral propriety, I mean, here I am on a pastoral call, so there I am shirtless. So, (laughing amid tears) finally Stephen says that he wanted everyone else to go. But he said, "I really want some time alone with you and once my family arrives tomorrow, you know, I don't know if that is going to happen." And he, he said "Would you come into bed with me so I can hold you?" So, uh, D-, F whatever in pastoral care and counseling. So there I am not only shirtless but I'm crawling into bed.

I: Did it feel like the right thing?

Schmidt: Oh, I had no choice. For some reason, I didn't feel like I had any choice to have my shirt taken off me either. It was a real stripping. But you see, what was happening was a real stripping, too, because (crying) all my defenses were going. Professional role and everything else. So there I am lying next to this person . . . and him holding me. And, uh, he said, "I want to tell you why I love you . . . And it wasn't as if he had any secret romantic attachment, you know, it wasn't any of that and he began telling me how he missed the night the search committee interviewed me so I was an unknown to him and he couldn't really vote for me but began to tell me just how I was the right person for the church and how much I was the right person for him and all the ways he was fond of me as a parishioner of his pastor and as a friend and colleague, and uh, I don't know about your life but in my life to have that said to me in that kind of directness, uh, it doesn't happen very often. . . .

I: Well, it sounds like . . . he was really aware of what he was doing and why he was doing it.

Schmidt: Yeah. And then as a response, I then felt that I needed to tell him, and so that in itself was growth, because not only was I someone that people didn't say that to naturally, I also did not say that naturally to people. . . . [S]o I told him why I loved him. . . . It was in some ways a holy week.<sup>23</sup>

In the interview, Father Schmidt went on to describe the entire course of Stephen's death and the funeral. This was the AIDS funeral that was repeatedly described as having the greatest effect on the parish.

Father Schmidt's experience of Stephen's death seems to parallel the parish's entire response to AIDS loss. Parishioners have experienced great vulnerability in their experience of loss and, time and again, have encountered God's presence amid the sadness and destructiveness of this loss. Vulnerability, therefore, appears to be a prerequisite for experiencing God's presence in a profound manner. Vulnerability includes the sense of "stripping of defenses" that Schmidt described so eloquently. The cause of vulnerability varies from person to person and occasion to occasion. For many in the parish, it was a consequence of tremendous loss. For others, it came about through an HIV diagnosis, while, for still others, it came about with sobriety. But however it occurred, in opening themselves up or in being opened through life and loss, parishioners came to know and understand how God was with them even in moments of pain. The fruit of this encounter with God at All Saints is a concern with justice. Having experienced God's love and presence profoundly, members of the parish recognize that they and *everyone else* are enfolded within this embrace of love and thus they feel compelled to offer this embrace of love to others. It is this experience and awareness that is at the core of the life and ministry of All Saints. Further, it appears that throughout his entire pastorate at All Saints,

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<sup>23</sup> Kenneth L. Schmidt, Rector of All Saints, interview by author, tape recording, San Francisco, 20 October 1999.

Father Schmidt has been continuing to assimilate and communicate his awareness of the relationship between vulnerability and love that he experienced most profoundly in his pastoral visit to Stephen. The next chapter shall explore further the relationships between loss, love and justice described above.

### Analysis of the Group Interview

One goal of this research was to understand the community's experience of bereavement. As a way of approaching this question, I conducted a group interview with several of the parishioners whom I had interviewed previously. Of the seven I invited, three were able to attend.<sup>24</sup>

This interview took place at All Saints on 25 April 2000. Two of the participants were gay men, the other was a heterosexual male. We began our discussion at 7 p.m. and concluded it by 9 p.m. I had prepared 8 questions: the interview protocol may be found in Appendix VI.

Analysis of the transcript yielded 32 concepts. These were grouped into 7 categories, and once again, these categories provide a summary of the interview contents. They include: the grieving process, the effects of AIDS loss on the parish, the future of All Saints, liturgy, AIDS deaths at All Saints, overshadowing losses and pastoral leadership.

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<sup>24</sup> Over the course of the interviewing, it became apparent that the experience of parishioners attending All Saints at the time of the first death of a parishioner was qualitatively different than that of parishioners who came later. As noted previously, the death of the first parishioner in the mid-eighties, William Rice (pseudonym) was a watershed experience for the people at All Saints because it brought home to them in no uncertain terms the fact they also were vulnerable to HIV. In addition, the experience of this funeral seemed to shape the AIDS "death imprint" for many, and in recounting the events surrounding this parishioner's death, most interviewees spoke of it with great emotion. In hearing their accounts, I felt that I was present at the funeral, such was the vividness of their recall. Both they and I were surprised by the amount of emotion attached to the memory of this event, as it had happened nearly 14 years prior to the interviews. Parishioners present for this death who are still at All Saints experienced the greatest amount of AIDS death, in general, including deaths of those inside and outside of the parish. For these reasons, I chose to limit the invitation to the group interview to parishioners who were present in the parish for that death.

Application of the paradigm model yielded the following narrative summary of the group interview: The story of All Saints emerging from the group interview is the story of a parish that sustained significant losses due to AIDS and, in one case, to cancer.<sup>25</sup> These losses included the deaths of members and non-members alike. Three of these losses were overshadowing for the parish: the first AIDS loss broke through the parishioners' denial about AIDS and generated great fear.<sup>26</sup> One consequence of AIDS was that the rector in the 1980s left as a result of his partner's diagnosis with AIDS. Another consequence was the flowering of lay leadership, particularly in the interim period.

During the interim period, the parish leadership actively searched for a new rector who would be sensitive to gay issues and be a good pastor and preacher. These priorities were articulated in anticipation of the imminent death of the most beloved member of the parish (i.e., Stephen Wilson) and of continuing AIDS deaths. The new rector arrived and was able to facilitate the parish's grief process for two other very significant members, in addition to the deaths of other members and non-members who were important to parishioners.

Several pastoral resources appeared to be key in facilitating the communal grief

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<sup>25</sup> The cancer death was the death of Mr. Neil Little, who died on March 8, 1993. His death was not AIDS-related, nevertheless, it constituted an overshadowing loss for the parish and was part of the cumulative loss the members experienced. See the discussions of Mr. Little's contributions and deaths on pp. 245 and 256 above.

<sup>26</sup> Interestingly, this fear manifested itself for some parishioners at the very heart of their life together: the Eucharist. One interviewee described his fear of drinking wine from the common cup in the early days of the AIDS epidemic when the cause of AIDS was still unknown. This anecdote is important because it demonstrates the courage and commitment with which parishioners met the epidemic. Despite his fears, this man continued to receive communion in both species because of the importance he placed on its reception. Interview with Tom Morris (pseudonym), tape recording, San Francisco, 28 September, 1999.

process: the pastor openly shared his own grief, he told warm personal stories about the beloved dead and he opened his home on several occasions so that parishioners could come together to mourn the loss of key members. The honesty with which the pastor and parishioners grieved was also central. Whenever possible, the cause of death was not hidden, nor was the sexual orientation or presence of the partner of the deceased. The other key pastoral resource was the liturgy, particularly funerals, which provided a context in which these meaningless deaths could be given some meaning. The liturgy also provided a place in which the unconditional love and acceptance of God could be experienced concretely. Finally, other important pastoral resources included the support members provided to one another, particularly to those among them who were caregivers, and the use of intercessory prayers.<sup>27</sup>

There were a number of consequences of the losses the parish sustained, including the loss of members, leadership, key functions, and finances.<sup>28</sup> Positive effects included stronger bonds between members of all types (i.e., gay and straight, men and women), increased commitment to the parish on the part of parishioners and an increased depth of spirituality and worship.

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<sup>27</sup> Two other pastoral resources mentioned by Father Schmidt include the custom of having a "second requiem" for the parish family on the Sunday following important funerals. As he noted, often the funeral itself was for the family and friends of the loved ones, whereas on Sunday, the parish could focus on its own sense of loss related to the death of important parishioners. Second, the parish designed and constructed an AIDS memorial shrine and garden. This became a gathering place on the occasions both of death and remembrance. The shrine has an image of St. Michael the Archangel, Defender of the Defenseless, who became the parish patron in the time of AIDS.

<sup>28</sup> With regard to key functions, Mr. Little was renowned in his role as greeter and caller for newcomers and as an evangelist. These qualities have been sorely missed since his death.

In anticipating its future, the parish expects to see more families and children as members, partially as a result of demographic changes in the neighborhood. Further, the fact that so many gay men have died in San Francisco has limited the numbers of gay men who might attend All Saints. The parish anticipates that the sacrament of marriage, as applied to same sex couples, will play a greater role in its future life, since one effect of AIDS has been to deepen the appreciation of lasting partnerships among gay men. Parishioners also hope that the wider church will remember the damaging effects that homophobia has had on familial relationships in the past and will take steps to be increasingly accepting of her gay and lesbian members.<sup>29</sup>

In conclusion, this interview was helpful in identifying concrete pastoral strategies that facilitated the entire community's experience of grief.

### **Conclusion**

Research at All Saints offers a number of intriguing findings. The most important finding is that a transcendent experience of love in the midst of loss provided many with a powerful experience of resurrection. A second important finding is the inextricable connection between resurrection life and justice in the parish, and we shall elaborate further on this relationship. Each of these emphases is associated, also, with the priority the parish places on inclusion and hospitality.

In responding to the experience of loss, the community of All Saints has embodied the truth that "dying is what the loving do," for they have lost many dear and

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<sup>29</sup> One of the interviewees noted that for many of the early AIDS funerals at All Saints, no family members were present. In general, it was only later in the epidemic that family members began to be more accepting and to attend funerals of their sons who had died of AIDS.

loving friends. The experience of repeated loss, its own form of death, has nevertheless resulted in new forms of life and hope in the parish.

Let us now turn to a closer examination of the theological and spiritual understandings of loss developed within the community through their experience of multiple AIDS loss.

## CHAPTER 8

### “WE ARE A PEOPLE WITH STARRY EYES”: THE THEOLOGY AND SPIRITUALITY OF ALL SAINTS

We are a people with starry eyes fixed on God’s horizon, looking for the homeland towards which we are journeying, having been given a vision that is not yet a reality.

This doesn’t mean that we ignore the present, that we cease to lament when present events seem to be leading away from the vision’s fulfillment. . . .

Our life is lived not just in the mean time, between promise and fulfillment, looking up at a dark sky, but in God’s time, in faith that the promise is being fulfilled, looking for the stars to come out one by one.

We have to remember that our vision of God’s kingdom includes all God’s children as numerous and varied as the stars in the sky.<sup>1</sup>

If there’s a resurrection, it has to be a resurrection that comes through the willingness of being able to face the stark reality of what you are experiencing.<sup>2</sup>

The purpose of this chapter is to describe the theology and spirituality of All Saints Episcopal Church as they have developed in response to the AIDS losses experienced by this community. The description is grounded in several sources of data: observations of the community’s worship and fellowship life, interviews with the church’s parishioners and clergy and responses obtained from the parish survey. My hypothesis, based on these data, is that the experience of AIDS loss at All Saints did not

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<sup>1</sup> Susan J. Singer, sermon preached at All Saints Episcopal Church, San Francisco, 9 August 1998.

<sup>2</sup> Kenneth L. Schmidt, interview by author.



dramatically change either the theology or spirituality of the parish; instead, the experience of loss deepened core beliefs and practices already present in the parish. In fact, the experience of living through the AIDS epidemic reinforced views long held by All Saints' most stalwart members: the belief that all people are God's children and worthy of love and care and that All Saints parish is called to express that love and care. Interestingly, these beliefs were forged in the fires of an earlier loss, the loss of many members in the 1960s who fled the parish because they could not accept the unwashed young who "occupied" the neighborhood in the latter part of that decade. As Leona Stark, one older member of All Saints noted when describing that exodus,

[T]he first loss was . . . a loss based on the fact that you run away from people who have less than you. You know, the people were leaving because Father Harris was feeding people who were hungry . . . people were disheveled in their dress . . . and the people [were] leaving because [they didn't want to sit beside those who were dirty] . . .<sup>3</sup>

All Saints' oldest members at the time of the AIDS epidemic were those who had chosen to remain at the parish during these difficult days in the community's life. Not only did they remain, but they welcomed those who came after them. Those welcomed included the increasing number of gay men and lesbians who found their way to the parish beginning in the late 1970s and early 1980s in the revival sparked by Neil Little and Lloyd Prator's evangelistic efforts. It was the hospitality of these older members that helped to set the tone for All Saints' extraordinary ministries of healing and presence amid the suffering of the AIDS epidemic. Thus, All Saints is a parish that has sustained not one, but two significant losses, and each of them has shaped the theology and

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<sup>3</sup> Leona Stark, interview by author, 10 September 1999, San Francisco, tape recording.

spirituality that I shall describe in this chapter. The thirst for justice associated with the second loss built on the inclusive theology and praxis birthed at All Saints in the 1960s.

### **The Theology of All Saints Church**

In assessing the effects of AIDS loss upon the members of All Saints, four key theologies appear to be central: a theology of God, a theology of resurrection life, a theology of church and ministry and a theology of the communion of saints. Let us explore each of these in turn.

#### **Theology of God**

Articulating a theology of God is a tricky business. It is fair to say that the experience of God common to the people of All Saints is much more than the sum of their individual statements about God. In fact, the most potent clues to the identity of the Divine, as experienced in the life of this parish, may not be found in what parishioners say at all; instead, it may be read through what they value and what they do! For example, the charm of the parish's liturgical space and appointments, the lavishness of its music, and the reverence and mystery of its Anglo-Catholic liturgy communicate the existence of a transcendent God, a God who inhabits a realm of beauty and awe quite unlike the grime and chaos of the parish's urban neighborhood. The solemnity of the congregation's worship contrasts sharply with the brashness of day-to-day life in the city and the parish's appreciation for the deep silence and nonverbal richness of liturgical prayer clashes with the breathless pace and cell phone chatter increasingly dominating the Bay Area. Viewed in these terms, their common life testifies to God as other: as One removed from mundane concerns, as a timeless peace, a still point amid the bustle of city life.

Yet there is another side to God as known at All Saints. The God who is worshipped and loved in this community is incarnational, present in the humblest events of the day and experienced in the authentic encounter between members and in the loving support they provide. However, an intriguing finding emerged from the research. Many more women interviewees than male interviewees described God as present, immanent, and humble. I interviewed more than by the men. I shall begin by describing their understanding of an immanent God and then turn to the more abstract notion of God that tended to be offered by the male parishioners.

The women I interviewed, particularly women who had been caregivers for those living with AIDS, expressed the view that God is present in the everyday and the ordinary. An exchange with Terry Cooper typifies this view:

I: So how . . . has your understanding of God, who God is and what God is like, changed?

S: I think God's a lot nicer . . . I always thought God was like my mother who would only love you if you were absolutely perfect and then only conditionally . . . God is kinder and more omnipresent and . . . humbler. . . . God [was] there when I gave this [cross] to Luciano and when I took it back from him [at the moment of his death] and [when I gave him] a spoonful of jell-o and [he didn't] barf it up, that [was] a holy moment.<sup>4</sup>

Terry went on to describe how Luciano had cared for her at an earlier time when he was well and she had been sick. He had made soup for her and she recognized that his act of caring was a sacrament of God's love. She realized that the same was true of her ministry to him while he lay dying. Thus, Terry learned of God's love through the

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<sup>4</sup> Terry Cooper, interview by author, 30 July 1999, San Francisco, tape recording.

experience of care giving -- as *she* increasingly incarnated love in her relationship with her dying friend, Luciano, she experienced God as more loving and accepting.

A similar understanding of God's immanence was expressed by another interviewee, a clergywoman, Judith Dunlop, who noted that she retained hope in the AIDS epidemic through maintaining a sense of God's presence "in the middle . . . of all this loss and despair." She noted that Christ was found in "the smaller miracles of community and relationship." God was found

in the small stuff. . . . Once I took [the parish's AIDS support group] when this guy Ken was dying and we went over to [the hospice]. It was probably less than a month before he died and he was just sitting there, he couldn't do anything for the most part, and he was so happy that we came and we had the meeting in his hospice room and you know it was so powerful and the thing that was so powerful. . . . here were these guys looking at their future in this guy who was really thin and weak and throwing up and we didn't run out of the room, we hung there watching this happen. I'm lifting up buckets of barf and meanwhile we're conducting this meeting and . . . Ken is talking about how much God loves him and that love is all around, and that he could see the love because we came. You know, there were just tears streaming down his face . . . because the guys had come to him and. . . sat with him, . . . [and] didn't flinch!<sup>5</sup>

She contrasted this "everyday" experience of God with the view that God would miraculously intervene to heal the sick. She said simply: "You knew better . . . so you had to look for the Christ presence somewhere else."<sup>6</sup> While the people of All Saints hold healing prayer in high esteem and make it available to one another on a regular basis, they learned through their experience of AIDS that healing comes in many forms.

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<sup>5</sup> Judith Dunlop, All Saints' Pastoral Associate, 1990-99, interview by author, 13 October 1999, Los Altos, Calif., tape recording.

<sup>6</sup> Ibid.

One of the most potent, experienced in their life with AIDS, was the increased ability to give and receive love.

Besides finding the presence of God in caregiving, others encountered God in the liturgy. In one of the most moving exchanges in the interviews, Lucinda Grey described to me how her view of God had changed through her attendance at funeral liturgies for persons with AIDS at All Saints. I asked her what effect the AIDS loss at All Saints had on her understanding of God and her relationship with God. She responded:

S: I think it's gotten me away from thinking of God as being very judgmental, and gotten me away from thinking that there are standards for behavior and belief that people need to follow to get God's approval and go to heaven. . . it's gotten me more to a conviction that whatever the life of the world to come may be that we'll probably all be there and that I don't think that God sweats the small stuff.

I: So what has that done for your relationship with God?

S: I guess deep down hiding in there somewhere there's probably a place where even I'm included . . .<sup>7</sup>

At this point, I asked her if she could describe what had helped her to arrive at this new understanding. She stated,

I've seen so many very good people that the vast majority of people would consider undesirable die in the church and have been to the funeral services with those hymns, with those readings . . . I cannot imagine that God would not accept Stephen Wilson, that he would not be pleased [with] Lars or Mike [or] any of those people. . .<sup>8</sup>

Clearly, through participating in the liturgy and prayers for her friends, Lucinda reached the conclusion that God is indeed merciful and that God's mercy extends to her, to her

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<sup>7</sup> Lucinda Grey, interview by author, 29 August 1999, San Francisco, tape recording.

<sup>8</sup> Ibid.

friends, and to others who may or may not be Christians, a point she later mentions explicitly.

Through living with AIDS and AIDS loss, each of these women experienced an increased awareness of God with them in the present moment, and their sense of God's love has grown along with this awareness. In contrast to the women at All Saints, most of the men interviewed held much more abstract and, in some cases, ambivalent notions of God.

Two of the men, Jan Herzog and George MacKenzie, described a movement toward greater spiritual searching as a result of AIDS. Jan, frustrated by religion's inability to provide satisfying answers in the face of AIDS, stated that AIDS

[has] definitely affected my method of, or my communication with, God . . . even questioning whether there is communication with God, especially when . . . there appear to be no good answers why.<sup>9</sup>

He described God as

a swirling mass of energy somewhere that I haven't put a finger on in a long time because I just erased . . . all of my stereotypical God-like attributes that I was raised with . . . you know, the old man with grey hair and a beard . . . .<sup>10</sup>

AIDS has moved God to the periphery of Jan's life -- in the past, God was more central.

Jan admits that, in placing God at the center, he gave God responsibility for his life rather than assuming more responsibility for it himself. Thus, he has gained a greater sense of power with this new understanding. At the same time, he also feels more struggle and uncertainty.

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<sup>9</sup> Jan Herzog, interview by author, 19 August 1999, San Francisco, tape recording.

<sup>10</sup> Ibid.

William Katz, an HIV positive interviewee, described a similar perplexity. As a result of difficulties he was experiencing with his treatment regimen, he lost the former confidence and closeness he had felt with God. He noted:

I'm not saying I'm abandoning God . . . I want a spiritual life and I don't know exactly how I want to have it.<sup>11</sup>

While AIDS has increased his gratitude for life, he noted that:

I am still working out who God is. I know we [Episcopalians] talk about the Trinity . . . I just talk about God . . . I still have some trouble coping with the Jesus story . . . I try to rise a little bit above some of the stories around that . . . I'm still working it out.<sup>12</sup>

The effect of this man's recent life with HIV disease, therefore, has been to create in him a sense of increased distance from God and uncertainty about God's nature.

Yet another HIV positive interviewee, George, described similar feelings of uncertainty associated with his illness. He stated:

I had a real crisis of faith . . . as to what God is, what Christ is, what any of that is. . . .<sup>13</sup>

He went on to say that he has never been a person to follow the "party line." Lately, he has tended to find the Spirit of God in the church itself, in the work it does and in the people who are there. Nevertheless,

there is a part of me that wants somebody to talk to and say . . . 'Why are you doing this? And . . . by the way, thank you, too.'<sup>14</sup>

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<sup>11</sup> William Katz, interview by author, 24 August 1999, San Francisco, tape recording.

<sup>12</sup> Ibid.

<sup>13</sup> George MacKenzie, interview by author, 26 October 1999, San Francisco, tape recording.

<sup>14</sup> Ibid.

George's sense of disconnectedness from God grew during the period of greatest loss and it was directly associated with his feelings of injustice surrounding the AIDS epidemic. Despite the disappointment he has felt with God, he still has not given up his search for meaning. A specific challenge he experiences is to integrate the God of his head and heart.

Other understandings of God offered by the men interviewed included a notion of God as the cohesive force in relationships, as "an impersonal, completely ineffably other . . . and also as consciousness and . . . something which we call love," and finally, a description of God as "isness," a notion of God that does not focus on who God is and what God does as much as on God as being.

I am somewhat puzzled by the gender differences in the understanding of God that arose in this study. Although the men's notions of God seem more abstract and impersonal, God does not seem any less important to the men than to the women. In fact, several men noted that an important effect of AIDS was to intensify their spiritual search. The men have a greater sense of anger toward God than the women do, however, regarding what they perceive as the injustice of AIDS. In this congregation only men died of AIDS -- part of the difference in understanding and relating to God may be a function of men's greater vulnerability to loss at All Saints. Further, a number of the men may feel thwarted in expressing honestly their anger toward God. Perhaps they fear that expressing their outrage will lead to a loss of faith. At least one interviewee, Jerome Washington, expressed this opinion directly. He was speaking about how he feels cheated with the loss of certain friends:

S:     Maybe I am angry at God, I don't know really . . . about that . . . I haven't



allowed myself to examine those feelings.

I:     Hmm. And do you have a sense of why that might be?

S:     Maybe because I am afraid that I might figure out . . . that I am angry at God.

I:     And then what would you do?

S:     Oh, I would wither on a vine, who knows? Get struck by lightening? . . . I don't know, I don't know. I would lose my faith . . .<sup>15</sup>

In further discussion, Jerome admitted that he has never totally lost his faith, despite the great number of losses he has experienced; however, his anger toward God seems to cover strong feelings of sadness and depression that are very painful for him to explore.

One consequence of AIDS loss, therefore, for a number of male interviewees is a sense of uncertainty and/or ambivalence about God. These feelings may also be associated with anger at the perceived injustices of AIDS. Addressing these feelings of ambivalence and anger toward God may be a key ministry in working with those experiencing traumatic AIDS loss.

### Resurrection Life

The most prominent theological category that emerged in the preached theology of All Saints is the notion of resurrection life. The theology of resurrection life at All Saints emphasizes the willingness to be vulnerable and to work for justice. Perhaps the clearest rationale for the relevance of resurrection to the AIDS crisis was articulated by Lloyd Prator, All Saints' former rector. When I asked him how his pastoral experiences

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<sup>15</sup> Jerome Washington, interview by author, 12 October 1999, San Francisco, tape recording.

with AIDS had changed his theology and ministry, he said:

I think before my experience at All Saints with AIDS [that] I was inclined to . . . embrace the notion common to much of American pop theology [that] we all believe the same thing, it doesn't make too much difference what you believe because we're all going to the same place and as long as you're a good person, everything is really fine. . . . And I guess somewhere in the middle of this I became a lot clearer that I am an Orthodox Catholic Christian. . . . As an example, a lot of people who are disinterested in Christianity will say, "I can know God in my garden because of the glories of creation." Well, the glories of creation is a bunch of hokie because creation is about death. Everything out there in that garden is winding down to death and unless you have a new act of creation, it's going nowhere. And I guess what I saw in the AIDS epidemic is people winding down to death and desperately needing that new act of creation that we call the resurrection.<sup>16</sup>

Prator felt that he was often privileged to stand at the boundary between death and resurrection in his pastoral ministry at All Saints.

Observations at All Saints revealed that one of the distinguishing traits of the parish was its firm belief in the power of the resurrection. I experienced All Saints as having a distinctive ministry: the ministry of comforting the bereaved and proclaiming the presence of God in sadness as well as in delight and celebration. This ministry follows directly from the understanding of resurrection life held by the rector, Kenneth Schmidt.

When I asked him about the meaning of resurrection, he responded:

Andrew of Crete, fourth century Bishop of Crete, referred to the cross as both the sign of God's suffering and the symbol of God's triumph and so for him, crucifixion and resurrection are one and the same thing. It's not that we wait for something to happen afterwards. [Resurrection] is the way we go through the crucifixion.<sup>17</sup>

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<sup>16</sup> Lloyd Prator, former rector of All Saints, interview by author, 18 October 1999, Sacramento, tape recording.

<sup>17</sup> Kenneth Schmidt, interview by author, 20 October 1999, San Francisco, tape recording.

Resurrection, in his view, does not depend upon a denial of death. In fact, he stated:

if there is a resurrection it has to be a resurrection that comes through the willingness of being able to face the stark reality of what you are experiencing.<sup>18</sup>

In other words, resurrection includes the ability to discern the presence of God amid pain and death. It is a form of healing that does not deny brokenness but that finds grace within it.

The notion of resurrection life at All Saints is characterized by particular qualities. First, living the resurrection involves courage and forgiveness, as reconciliation is a potent form of resurrection. Second, resurrection involves the willingness to face the death within us and to be surprised by God. Thus, vulnerability is a prerequisite for the experience of resurrection. Further, resurrection may be found anywhere and everywhere -- we can experience new life in any aspect of our existence. Resurrection also appears to be something that we may experience repeatedly in our lives. As Susan Singer, pastoral associate noted:

Dying and rising from the dead take a lot of practice and we need to see Jesus do it several times if we're going to get used to the feeling. Letting others see God at work in our lives, with us in death and raising us to new life in Jesus; being willing to let that show in all its messiness and incompleteness, as we struggle to let it happen and as our hearts are troubled as we face it yet again, may be one of the most important things we are asked to do -- that and being with others as God is at work in their lives, as they see the terrible glory of Jesus crucified and risen, as their hearts are troubled, as they are entangled with death and waiting for new life.<sup>19</sup>

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<sup>18</sup> Ibid.

<sup>19</sup> Singer, sermon, 9 April 2000.

Through the course of my time at All Saints I became convinced that the people of All Saints do not shrink from death. This characteristic distinguished the congregation from many others. The experience of death has been intricately woven into the fabric of their common life, and they are more than willing to talk about it, to reflect upon it and to comfort those who are staring it in the face. While fear of death is not totally absent at All Saints, acceptance of death as part of life is a characteristic of this community.

Perhaps the most surprising twist on resurrection theology at All Saints, however, is the intricate connection between new life and justice that is part of the proclamation of the resurrection. This connection was expressed by the rector most clearly in a sermon on the "Lazarus syndrome" following the murder of Matthew Shephard. In this sermon, Kenneth Schmidt reflected on what it means to become a human being again following near death from AIDS or other life threatening events. He noted that survival requires that we prevail -- if we are to live rather than merely survive following a brush with death, we must commit ourselves to values of justice and peace and set them ever before us. This understanding of resurrection in terms of justice was shared by others in the congregation. Several interviewees felt that the problem of AIDS requires a cosmic form of justice. That is, there must be some compensation for the pain and stigma those living with AIDS experienced. This understanding was expressed most forcefully by the two HIV positive men interviewed. The first, William, stated:

I think a lot of AIDS patients have paid very high prices for their lives and I mean death is rarely a painless experience for anybody, but I think especially for AIDS patients, it can be really excruciating. . . . I always pray to God that God will honor the trials of these people and draw them close and give them the peace and the lack of pain and the wholeness and the lack of struggle . . . I

really wish that for them in whatever form it takes.<sup>20</sup>

The second HIV positive man, George, clearly has wrestled for years with the injustice of AIDS. In attempting to find a resolution to this perceived injustice, he also looks to the afterlife as one place where it may be found, noting that:

if there is justice in this world . . . there has to be life after because that is the proof of the justice . . . because, you know, somebody lives a hard life, but a good life, and you know there would be final justice in the fact that there is something afterwards.<sup>21</sup>

On the one hand, George doesn't rest easily with this notion of the afterlife, yet on the other hand, he believes that he and others working for justice in the face of the injustices associated with AIDS are upheld by the spirit of those who have died.

I guess I would like to think that somehow or another a spirit is there and that people are joined with . . . God and that is the moving power . . . of justice and good on the earth.<sup>22</sup>

In other words, there is an empowerment for the living that comes from the combined spirits of people who have died that redeems some of the present unfairness associated with AIDS.

While the remarks of William and George seem to imply that justice is most clearly achieved in the afterlife, it is also fair to add that George, in particular, described the Church's need to fight *now* against the intolerance that is associated with homophobia and AIDS. He noted:

In spite of the growing numbers of infected [women, especially women of color, men of color and drug abusers, AIDS] is overwhelmingly a gay disease in San

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<sup>20</sup> William Katz, interview by author, 24 August 1999, San Francisco, tape recording.

<sup>21</sup> George MacKenzie, interview by author, 26 October 1999, San Francisco, tape recording.

<sup>22</sup> Ibid.

Francisco. And nationally, not quite as overwhelming, but . . . certainly predominantly so. And . . . the church has to do more about teaching . . . tolerance because the church itself is pretty intolerant.<sup>23</sup>

One concrete vision of justice that emerged in the interviews is the belief that the blessing of same sex unions by the Episcopal Church could provide a potent expression of resurrection life. In fact, Anna Magdalena described a move in this direction as a resurrection of the sexual revolution that died with AIDS, a resurrection

to live a free and loving life on a higher plane. The freedom would be more attached to a higher level of interaction and a higher level of commitment and a higher level of responsibility for the well-being of those around us . . . a more Godlike way of expressing love.<sup>24</sup>

A number of my interviewees expressed the view that one positive outcome of AIDS has been a deepened appreciation of relationships within the gay community -- All Saints' members hope that the wider church will contribute to this particular form of resurrection through increased acceptance and blessing of same sex love.

The people of All Saints are not naïve, however, about the gap between their vision and the vision of the wider church on issues of inclusion. This gap was painfully heightened by the resolution of the Lambeth Conference in August of 1998, in which the Bishops of the Anglican Communion rejected "homosexual practice as incompatible with Scripture."<sup>25</sup> It was in response to this statement that Susan Singer preached the sermon on faith with which we began the chapter. She acknowledged:

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<sup>23</sup> Ibid.

<sup>24</sup> Anna Magdalena, interview by author, 13 September 1999, San Francisco, tape recording.

<sup>25</sup> Lambeth Conference, Section I. "Called to Full Humanity," Resolutions, 1998 [text on-line]; accessed 16 March 2001; available from <http://www.justus.anglican.org/resources/Lambeth1998/LC98res/sec1.html>.

At the Lambeth conference this week, a majority of Anglican bishops worldwide signed a statement on human sexuality based on a vision of the Christian community that is not the same vision that God has been giving us in this diocese, in this city and in this parish. It is a vision that moves away from the full inclusion of all people, of every sexual orientation in God's kingdom.<sup>26</sup>

While the people of All Saints long for a resurrection life characterized by justice and the loving embrace of all people, they remain quite aware that the new life they seek is not fully realized. Nevertheless, they persist with the Church and they persist with their vision, in part, because of their faithfulness to the memories of their loved ones whose deaths cannot have been in vain. They persist, also, because the communion they experience with one another overcomes the disconnection they feel from the church at large. They experience God's partnership with them in the continuing crucifixion of intolerance and together, in God's presence, they find strength to move toward the new life they desire for themselves, for the larger Church and for all people in need of God's love.

#### Ecclesiology and Ministry

The theology of church and ministry at All Saints emphasizes unity, shared ministry and the church's role in promoting justice and human dignity. All Saints is first and foremost a baptismal community. This aspect of its identity is expressed most clearly in the emphasis the congregation places upon the Easter Vigil. The Vigil is the premiere liturgical event of the year: it is well rehearsed, carefully orchestrated, and fully sensory. The congregation revels in the rich symbolism that communicates truths about the

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<sup>26</sup> Singer, sermon, 9 August 1998.

paschal mystery so central to the congregation's life. The two-hour service culminates with a festive potluck in the parish hall. It is fair to say that the Vigil is for the congregation, while the somewhat anticlimactic Sunday morning Easter Eucharist is for the larger community.

The Sunday celebration of the Holy Eucharist is at the center of the parish's life. This reunion of the baptized remembers and re-enacts the mysteries of Christ's death and resurrection. The liturgy is richly Anglo-Catholic. It is carefully choreographed, solemn, reverent and prayerful. At the same time, however, the congregation does not take itself or its piety too seriously; sermons, for example, contain quite a bit of humor, including some self-deprecating jabs.

Even with the rather "orthodox" Anglican sacramental emphases, the congregation's emphasis upon inclusion has encouraged members to stretch the boundaries of Eucharistic practice in the service of hospitality. The most notable example occurred at Stephen Wilson's funeral. Stephen Wilson's partner, Paul, who is Jewish, occasionally accompanied Stephen to the Eucharist for holy day services. When he attended, he was in the habit of coming to the altar with Stephen for a blessing during the distribution of communion. At Stephen's funeral, Paul came forward as usual and, according to Father Schmidt

perhaps because of some confusion, but also I think because of the grace of God, rather than this great division of all the Christians coming forward and all the Jews staying in their seats, all the Jews came forward, too. And I think that [some of the Jews,] at least the first one next to Paul assumed that Paul had taken communion. . . . And so the first one whispered to me, 'May I take communion on Stephen's behalf?' And I said, 'Of course.' So suddenly I'm serving communion to all these Jews. We lost a parishioner over that . . . who was furious over this great violation. . . . But it was a transcending moment . . .



Through this experience, the parish came to a new understanding of unity and inclusivity, and it resulted in a new practice. As Father Schmidt noted:

We used to have in the bulletin what lots of churches say, thinking that it's inclusive, 'All baptized Christians are welcome to receive.' We just changed it, we just threw that out. I didn't know how to reword it for a long time. But I decided no more just offering to the baptized Christians, that Baptism itself even though Christians talk about it as if it were inclusive, it's exclusive to those who aren't, including some Christians like Quakers.<sup>27</sup>

The worship bulletins at All Saints now state that "All who desire to grow in the love of God and neighbor are welcome to receive communion." Further, they provide specific instructions about the reception of communion for those who may be unfamiliar with the practice. This concrete example speaks clearly to the priority the congregation places upon extending God's love to all. It also highlights the role that AIDS played in heightening this priority. The example suggests, further, that the unity of the baptized reflects an even greater unity among all people, for all are included in the embrace of God's love. Through this Eucharistic practice, the people of All Saints communicate that their ministry of hospitality mirrors God's embrace of the whole world. All Saints' parishioners recognize difference, certainly, but they do not allow it to divide.

Ministry at All Saints may best be characterized as collegial. The rector routinely shares both preaching and presiding responsibilities with the associate clergy. Preaching is also shared with theologically educated laity. Further, All Saints has engaged in several ministerial partnerships, most notably in recent years with St. Cyprian's Episcopal Church, a predominantly African-American congregation in a nearby neighborhood. For over a year, the churches shared clergy and attempted to draw strength from one another

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<sup>27</sup> Schmidt, interview.

in certain program areas and in special occasions of worship. At the present time, due to staffing changes, the partnership is somewhat attenuated, but the two churches maintain close ties.

The people of All Saints understand ministry as an expression of the Baptismal covenant. The covenant emphasizes the centrality to a Christian life of worship, prayer, fellowship, repentance, proclamation, service and advocacy for justice. Ministry is not understood as primarily intended for the congregation or for the church. Instead, it has been described as “how we consciously express our connection to God through Jesus Christ in every moment of our lives.” In the last two years, time has been set aside after the main Sunday service during the Sundays of Advent to commission the laity for their ministries in the world. Despite the stated emphasis on ministry in the world, however, the congregation and rector do highly reward laity who assume responsible positions of leadership within the church. Office holders of various sorts are commissioned regularly within the Eucharistic context.

The effects of AIDS loss upon the congregation and its ministry have been felt in several ways. First, as noted above, the interim period witnessed a flowering of lay leadership that has continued. Second, the many deaths to AIDS caused significant turnover in key leadership positions. The effect of this loss was to “promote” to leadership members who might have been more reticent about assuming key leadership positions in a less critical time. Third, a primary effect of AIDS has been to draw the members of the community together in closer relationships. This closeness has been expressed in the collegiality characteristic of All Saints ministry in recent years. Finally, the most significant effect of the AIDS epidemic was to promote a level of intentionality

and seriousness within the congregation that was not present to the same extent before it.

As one participant in the group interview, Tom Morris, noted:

[as a result of AIDS] I think that the quality of the worship and . . . the quality of the parish changed. I think that before that it was a little bit more superficial. I remember when Lloyd was here, he would complain about people, people had no commitment, it was here today and gone tomorrow, it was kind of like a drive by parish . . . and they would leave when they got bored with it and you don't have that anymore. I think there's a lot more commitment to the parish and I think the spirituality is a lot deeper.<sup>28</sup>

In all of these reflections on ecclesiology and ministry, some dominant patterns emerge. The net effects of loss have been to strengthen community ties, to increase the emphases upon inclusion and unity, and to deepen the liturgical and spiritual lives of the community and its members.

#### Communion of Saints

As noted previously, All Saints is exceptional in its emphasis upon remembrance.<sup>29</sup> Through sharing stories and honoring memory in memorial gifts, the congregation experiences a vital sense of connection to deceased members. The cherishing of memories serves at least two purposes. First, it is a tangible expression of unity in love that transcends this life. Second, remembering deceased loved ones empowers the congregation and its members in the quest for justice. Each of these purposes reflects the essential nature of the communion of saints as a union in love and remembrance that nurtures and empowers Christian ministry.

All Saints, therefore, may be characterized as a community of memory. Besides

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<sup>28</sup> Tom Morris, group interview by author, 25 April 2000, San Francisco, tape recording.

<sup>29</sup> See, for example, p. 277 above.

speaking about the beloved dead, the members pray for them, and this practice of prayer is central to the parish's life. Each September the congregation holds a service of remembrance for those who have died of AIDS on the Sunday closest to the feast of St. Michael the Archangel. During the height of the epidemic, the parish adopted Michael, "Defender of the Defenseless," as their patron. The beautiful outdoor garden and shrine adjacent to the church are named in his honor, and they were constructed specifically to assist the congregation in honoring those who died from AIDS.<sup>30</sup> At the last memorial service, the names of 91 persons who died with AIDS were read.

To worship at All Saints on a regular basis is to become familiar with the stories of Stephen Wilson, Neil Little and other deceased members important to the congregation. These stories are shared most often by Father Schmidt in his homilies, but other members refer to them as well. The pastoral practice of sharing warm personal stories played an important role in facilitating the communal grieving process.

As a concrete expression of its belief in the tangible importance of memory, the congregation has committed itself to the construction of a columbarium. This memorial is currently being installed in the rear of the church, and it will hold the ashes of departed members as well as the ashes of current members upon their death. Its presence will make the faithful departed an even more integral part of the church's life.

The presence of many beautiful memorial gifts brings to mind generous benefactors who have died. Lovely Persian rugs grace the sanctuary and main aisle, and these were the gift of a young man who died of AIDS. Stephen Wilson's generosity

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<sup>30</sup> See the connection between Michael the Archangel and the plague on p. 160 above.

helped to provide the parish organ and to underwrite a major renovation of the facility. The presence of some generous bequests has also eased the financial strain that often accompanies life in a small parish.

Perhaps, however, the most important influence of the congregation's beloved dead is the commitment of members to alleviate injustices that contributed to the untimely deaths of many to AIDS. I have already described how at least one member, George MacKenzie, explicitly derives strength in his own work for justice from the knowledge that his friends who have died are supporting him in his efforts. Understood in this way, the memories of the many who died at All Saints may be understood as "dangerous" for they undermine the complacency and denial that allowed AIDS to become such a widespread threat to life and health in the gay community and beyond. It remains to be seen to what extent the congregation's memories of its own loved ones who have died will continue to fuel members' advocacy for the millions around the world -- straight and gay -- who still suffer from the ravages of AIDS.

The theology of the communion of saints at All Saints, therefore, is reflected in the work of remembrance. In the celebration of the Eucharist central to the parish's life, past, present and future come together in a sacredly constituted moment that makes absent loved ones seem, at times, to be tangibly present. Re-membrance of loved ones paired with the Christian eschatological hope expressed in the Great Thanksgiving endows the unity so central to this parish's identity with a transcendent power. It is this power that provides the fuel for the parishioner's efforts toward justice. The thirst for justice, present before the ravages of AIDS at All Saints, has been strengthened and made more concrete through the parish's AIDS losses.

In conclusion, therefore, the theological effects of AIDS upon All Saints are reflected in changed understandings of God and in a notion of in resurrection life characterized by openness to vulnerability and a thirst for justice. Further, AIDS losses have deepened members' appreciation of the church as community, while increasing the hospitality of their Eucharistic practice. Finally, the understanding of the communion of saints emphasizes a unity in love that transcends time and empowers the members' quest for justice.

### The Spirituality of All Saints Church

Drawing on the understanding of spirituality presented earlier, I would propose that two key elements of spirituality, a movement toward self acceptance and an increased capacity for self-transcendence, characterized the response to AIDS at All Saints.<sup>31</sup> Self acceptance is expressed in the members' increased willingness to accept the reality of their vulnerability and the limited nature of human life. Self acceptance is also expressed in the members' increased ability to live in the present and in an enhanced gratitude for life. Finally, the honesty of the parish's life with AIDS also indicates a capacity for self acceptance. The increased capacity for self-transcendence, on the other hand, is reflected in the parishioners' expanded horizon of meaning and in the emphasis they place on community, liturgy, prayer, music and the quest for justice. These practices provide important avenues for communion with God and others that move members beyond the narrow self concern that can be crippling in the aftermath of loss.

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<sup>31</sup> See the discussion in Chap. 4 on pp. 117-21 above.

The spirituality of the members of All Saints Church was undoubtedly intensified by the experience of traumatic loss. The AIDS epidemic was a crisis, and in coping with it, members inevitably found themselves wrestling with spiritual concerns. For example, when I asked Jerome about the effects of AIDS loss on his spiritual life, he stated:

It kind of put it in my face . . . I had to deal with it . . . I could be begging God or angry at God, but it was always there. . . . I couldn't just coast and relax. I mean, I could choose to ignore God, but I think my response usually was . . . to deal with the spiritual dimension because it was . . . forced on me.<sup>32</sup>

The experience Jerome recounts seems typical for the members of All Saints, for many described the way in which their attempts to come to terms with AIDS precipitated a spiritual search. As we have already noted, this search continues for many members, particularly the men of the parish.

### **Self Acceptance**

Turning first to self-acceptance, one fruit of the encounter with AIDS for some parishioners was an increased awareness of and acceptance of their mortality. Many members commented in the interviews on the premature encounter with death experienced with AIDS. With that encounter came an increased appreciation of their vulnerability. As Michael Wallace put it:

I think the deaths had a huge impact . . . You know living through pain like that and . . . prematurely living through it when we're not supposed to be at that point in our lives . . . I think it changed a lot of people's lives and the way they acted . . . I think a lot of people realized how vulnerable they were and that they don't really control their lives.<sup>33</sup>

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<sup>32</sup> Washington, interview.

<sup>33</sup> Michael Wallace, interview by author, 27 August 1999, San Francisco, tape recording.

For some parishioners, this increased awareness of their vulnerability and mortality led ultimately to a greater acceptance of death in general. Here, Tom's response may be considered representative. When asked how AIDS had affected his life, he stated:

It has caused me to think a lot more about death. I have been to so many funerals that I can't help thinking about my funeral. . . . being in a period of plague and seeing so many funerals makes you think about life and death differently.<sup>34</sup>

He went on to describe a somewhat dangerous vacation he had taken recently and the way in which he matter-of-factly prepared for the small probability of death before he left.

Despite the risk,

I was very at peace because I really wanted to do this and I felt if I die, this is OK. I mean, I am almost 50 years old. Ever since I've gotten to the age I am now, I just feel a little bit less afraid than I used to be. I don't want to die . . . I want to live, but I'm not as afraid of [death].<sup>35</sup>

Life with AIDS, therefore, increased Tom's comfort with the anticipation of his death.

A second aspect of self-acceptance is the increased ability to live in the present and to live with gratitude. Jan talked about how AIDS increased his ability to appreciate the present.

You know, we put too much emphasis on what's going to happen five years down the road. . . . I'm worried about retirement, I'm worried about . . . am I going to have enough money . . . And yet, damn, we just need to live, this is an important day, and it's a hard thing to do. My parents had this depression mentality . . . I really want to break that. I mean, I know I can live and I know I can make money and I know that I can survive and I've got to learn how to be happy with that instead of being a crusty old unhappy guy with lots of money

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<sup>34</sup> Morris, interview.

<sup>35</sup> Ibid.



. . . It's definitely changed my whole outlook on life.<sup>36</sup>

A third interviewee, Leona, described how the awareness of AIDS deaths in the parish increased her gratitude and appreciation for life. She noted that

. . . when an 80 year old person passes away, you say, well, they lived a good life and . . . God bless them . . . and you know they're on their journey elsewhere, but when you're losing people 30 years old and 40 years old and 20 years old, it really makes you stop and think . . . you have to be grateful and thankful that the Lord allows you to get up and smell the fresh air in the morning and say, "Thank you, Lord, for helping me get up and smell the fresh air and be in my right mind, because everybody is not able to get up and say that and we're in a church where you hear about another funeral and another funeral and it does, in fact, affect you."<sup>37</sup>

The responses of each of these interviewees suggest that the fruits of their encounter with AIDS lie in a greater acceptance of their own mortality and an increased ability to live in the present moment. For other members, the encounter with AIDS was an incentive to embrace sobriety: this also provided an enhanced appreciation of vulnerability that was quite healing.

For some members, the acceptance of mortality -- their own and others -- was not achieved without conflict or struggle. At least one lay member of the parish dramatically experienced his own limits in coping with a friend's plan to prematurely end his own life. This occurred when the suffering his friend anticipated from his AIDS-related opportunistic infection was more than he could bear. His friend was told:

"Your pneumocystis keeps recurring and we can't treat it anymore. You've got about two weeks to live and the last week of your life is not going to be pleasant. . . ."<sup>38</sup>

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<sup>36</sup> Herzog, interview.

<sup>37</sup> Stark, interview.

<sup>38</sup> Silas Manning, interview by author, 14 October 1999, Berkeley, tape recording.

At that point, his friend called his family and began to formulate a suicide plan. Despite his own reservations about suicide, the parishioner helped his friend to obtain the information he needed to die with dignity. He said:

I suppose that felt to him like I was condoning what he was doing, and I guess I was, this was a matter that I have conflicted feelings about [as a result of my religious upbringing and attachments] . . . you understand that there are certain teachings of the church that I value about human life, but . . . I also don't understand sticking around for two weeks worth of agonizing dying. I had seen other folks do that.<sup>39</sup>

This parishioner made himself available to his friends' family members both before and after the suicide. This story demonstrates that several members of All Saints faced very difficult decisions during the height of the epidemic, and often there was no easy resolution to the quandaries they faced. Certainly, facing these difficult decisions only heightened their awareness of human limitation and the fragility of life.

Another important effect of AIDS upon the spirituality of All Saints was the way in which it enhanced the parishioner's appreciation for honesty. In the course of the epidemic, parishioners learned of the value of facing the pain of AIDS head on. Michael described the importance of "talking about it, being open" sharing about AIDS and about the losses he had experienced. This lesson was reinforced when a close friend of his died -- Michael attributed his premature death, in part, to his denial. In his view

one of the things that made AIDS difficult was [that] it started out having to be such a secret . . . [that] cause[d] a lot of people to want to hide and deny it and that paralyzed a lot of the feelings associated with it.<sup>40</sup>

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<sup>39</sup> Ibid.

<sup>40</sup> Ibid.

Secrecy and dishonesty were difficult because, in the end, they robbed people of the very emotional support that people at All Saints learned was essential in coping with loss.

One attribute of the parish important to many is that All Saints is a place where people feel free to be themselves. The value the church placed on authenticity was to bear fruit in the AIDS epidemic, because it allowed members to mourn in a genuine way. Some members had the unpleasant experience of attending funerals in other churches in which important aspects of the deceased's identity and lifestyle were hidden -- this was not the case at All Saints, and it is part of what facilitated the healing process in loss.

In summary, AIDS influenced members' spirituality by increasing their self acceptance. This effect was noted in increased awareness of and acceptance of mortality, in an increased ability to live in the present, and finally, in the degree of honesty with which members were able to mourn losses.

### Self-Transcendence

The second important aspect of spirituality, self-transcendence, had several manifestations at All Saints. Members described the way in which living through a period of great loss caused them to re-evaluate their existing beliefs and to look for new meaning, particularly as their existing sources of security were shattered.

Members of All Saints who encountered enormous loss spoke of the tremendous emotional impact of this experience. Jerome noted that in the period of greatest loss there was both a sense of personal connection with those who had died and a sense of personal distancing:

For me, it was always a balance between . . . wanting to embrace the whole world and then wanting to shut it all out . . . and all the distancing, I think, was because

of the fear of being totally overwhelmed, totally crushed by the whole.<sup>41</sup>

At the same time, he also remembers a heightening of perception during that time:

S: . . . thinking back to that period when [AIDS] was so much a part of everyone's life, [it] just elevated everything to a new level. . . . It was such a profound experience to be in the presence of so much loss that was unexplainable that . . . every person became more precious

I: Uh huh. And pain became more painful. And joy was more joyous.

S: Yeah. That was my experience. And I think also . . . especially being a gay man . . . the added edge knowing that, you know, this cold I am catching . . . is this the last disease I get? . . . Is this the beginning of the end?<sup>42</sup>

This heightened perception of life encouraged parishioners to expand their horizons of meaning and to reach out in new ways to God and each other. One result of the search for transcendent meaning in the epidemic was an increased sense of community. The spirituality of AIDS at All Saints was, first and foremost, a spirituality of friendship. For example, Jerome notes:

One thing I want to mention that is important is the sense of support. I can remember a close friend that was dying in the hospital and I would always go with a group to visit. You know, go with two or three other people, never alone, and he was just surrounded by love. Ah . . . there was so much caring, love and support and . . . people showed up, people were present for their friends.<sup>43</sup>

Thus, a major effect of AIDS was to deepen the ties among friends.

Referring specifically to this phenomenon in the parish, Silas stated that

I think the HIV epidemic did a lot to strengthen the communal ties . . . because people were grieving and let each other grieve and were good about providing support and giving people freedom to mourn. . . . I think that the AIDS

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<sup>41</sup> Washington, interview, 12 October 1999.

<sup>42</sup> Ibid.

<sup>43</sup> Ibid.

epidemic was bad enough that guys particularly had to, were pushed into letting their grief show and that formed a much stronger communal bond than would have happened otherwise.<sup>44</sup>

In the group interview, the parishioners affirmed this assessment and noted that, while the open expression of emotion Silas described formed bonds among the gay men of the parish, it also helped to strengthen bonds across constituencies: between men and women and straight and gay members of the parish. As a consequence of his experience of HIV, one parishioner's understanding of God as the cohesive force in relationships was strengthened. In his view,

it reinforced my understanding of God as this relationship force . . . because of the relationships that I've developed through the disease and through involvement with people in general . . . AIDS being what it was, it caused people to get in relationships a little more readily . . . than just the normal day to day life. In the gay community, of course, it was something that everyone identified with, everybody identified with the loss . . . so it had this effect of just developing that relationship aspect.<sup>45</sup>

Thus, an important effect of life with HIV/AIDS at All Saints was to increase the members' appreciation of their friends who shared the experience of loss with them.

Besides contributing to greater self acceptance, as noted above, the increased honesty characterizing life with AIDS had another important benefit to the community.<sup>46</sup>

It allowed the parish to embrace openly those who were suffering, and the members grew in caring for them. As Jerome noted in the group interview:

I was talking to a . . . woman a few years ago who goes to a fundamental black church in Oakland and there were a few people with AIDS and they just kind of dropped out of the church and dropped out of the community because that was

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<sup>44</sup> Manning, interview.

<sup>45</sup> Wallace, interview.

<sup>46</sup> See p. 274 above.

what was expected to happen . . . they stayed home and they missed out on the support of the church and the church missed out on the experience of supporting them.<sup>47</sup>

All Saints parishioners learned of the transformation that comes through providing care, and during the epidemic, they particularly supported their members who heroically provided care to the dying.

Besides finding transcendent meaning in community and caregiving, the people of All Saints also derived support from their rich liturgical life, from prayer and from the arts. One of the overwhelming impressions I formed during my first Holy Week at All Saints was the way in which the rich heritage of Anglo-Catholic liturgy provided a strong container for the many and varied emotions associated with loss. The nonverbal richness of the liturgy and its sheer beauty facilitated experiencing and expressing the heightened joy and sadness that were a part of life with AIDS. I have hypothesized that one reason why All Saints survived the epidemic as well as it did is because the parish's liturgical life was robust enough to hold and to interpret the painful emotions that arose in its life with AIDS. Further, several parishioners described the importance of the parish's practice of intercessory prayer to their own healing amid sickness and loss. In the group interview, when asked how membership in the parish had helped to facilitate the individual experience of grief, Jerome noted the importance of having a place where he could talk about his losses and where he could have others join him in praying for his friends. He found it helpful to

get . . . the name of a loved one on the list and [know] that the community

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<sup>47</sup> Washington, group interview by author, 25 April 2000, San Francisco, tape recording.

is praying for that person, even though they don't know who it is. . . . That's always been important for me. . . .<sup>48</sup>

Intercessory prayer, therefore, provided a concrete way in which the community could help to share the individual burdens of pain.

During the individual interviews when members of the parish were asked to describe the religious and spiritual resources most important to them in coping with AIDS loss, the resource mentioned most frequently was the psalms. Psalm 91, in particular, was important to many during the AIDS crisis. Father Schmidt's interest in the psalms of lament helped the members of All Saints to move toward a more honest expression of their feelings towards God. Other forms of prayer that seemed helpful were repetitive prayers, such as the rosary, the Jesus prayer and the use of mantras which have a calming effect in times of crisis.

Yet another source of transcendence was music. For a church of its size, All Saints is blessed with an amazing depth of musical talent. Singing certain hymns facilitated the expression of emotion. Perhaps one of the most important was a hymn used at Stephen Wilson's funeral and, most recently, at the AIDS memorial service:

I'll praise my Maker while I've breath;  
and when my voice is lost in death,  
praise shall employ my nobler powers.  
My days of praise shall ne'er be past  
while life and thought and being last,  
or immortality endures.

How happy they whose hopes rely  
on Israel's God who made the sky  
and earth and sea with all their train;  
whose truth forever stands secure,  
who saves the oppressed, and feeds the poor

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<sup>48</sup> Ibid.

And none shall find his promise vain.

The Lord pours eyesight on the blind;  
the Lord supports the fainting mind  
and sends the laboring conscience peace.  
He helps the stranger in distress,  
the widowed and the fatherless,  
and grants the prisoner sweet release.

I'll praise him while he lends me breath;  
and when my voice is lost in death,  
praise shall employ my nobler powers.  
My days of praise shall ne'er be past  
while life and thought and being last,  
or immortality endures.<sup>49</sup>

This hymn expresses the hope felt by many in the congregation in the continuity of life.

As we have already noted, the hope for resurrection is inextricably bound at All Saints with a desire for justice, and this hymn summarizes the confluence of this hope and desire in a powerful way.

A final transcendent hope for All Saints is the belief in God's justice. This hope is both a present and an eschatological hope. It is most vividly present in the makeup of the community itself. All Saints is comprised of people, who though marginalized by the wider Church and society, tenaciously cling to a vision of wholeness grounded in the love of a God who embraces all. The ravages of AIDS have served to impress more deeply upon the members of All Saints the depth of that love and the wideness of God's embrace. The eschatological hope is the vision of inclusion birthed in them through the pain of loss.

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<sup>49</sup> Isaac Watts, "I'll Praise My Maker While I've Breath," Hymn 429, *The Hymnal*, 1982 (New York: Church Hymnal Corporation, 1982).



### Summary: The Effects of AIDS Loss on All Saints

As this review has indicated, the effects of AIDS loss on the congregation have been varied. The following summary may help to highlight some of the most significant effects.

#### Parish Life and Leadership

- The members of All Saints experienced a staggering amount of loss to AIDS. These losses were of parishioners and non-parishioners alike. Some male members experienced the loss of nearly their entire generation to AIDS.
- AIDS had a significant effect on parish leadership. As one consequence of AIDS, the parishioners lost the rector, Lloyd Prator, who helped to inject new life into the Church in the 1980s and who spearheaded a compassionate response to AIDS in its earliest days. During the interim period, the strong lay leadership of the parish grew, and this development paved the way for a more collaborative style of leadership with the arrival of Kenneth Schmidt. However, well into the 1990s, the parish continued to experience the loss of major leaders and many parishioners were called upon to fill the resulting gaps.
- One outcome of the losses was growth in the parish endowment due to bequests. This has helped somewhat to ease the financial stresses experienced by the loss of some of the parish's major pledgers to AIDS.

#### Theology

- The most profound theological effect of AIDS loss is the awareness of resurrection life, the presence of God's love amid pain and loss. The members of All Saints have experienced this love concretely. Its most crucial effects upon them are an awakening of their desire for justice and an increased awareness of the need for hospitality to all.
- The effects of AIDS may be seen throughout the church's buildings and grounds. The beautiful Oriental rugs that grace the sanctuary were left to the parish from a man who died of AIDS. Further, as a result of the endowment, the parish was able to pay off its organ and make improvements to its physical plant. The presence of the AIDS shrine and garden add to the beauty of the facility. The placement of the columbarium, due to arrive in July of 2000, will increase the sense both of the presence of the beloved dead and of the unity the parishioners feel with them. These aspects of the parish's life emphasize the importance of remembrance, an aspect of the communion of saints.

- Besides its effects on the parish's physical space, remembrance was also accentuated by key pastoral practices that Father Schmidt developed to ease the community's grief. These including storytelling, the hosting of wakes in the parish rectory, and the development of a second Sunday requiem for parishioners following a key loss. Further, parishioners banded together to create AIDS quilts for several of their deceased members.

### Spirituality

- One consequence of AIDS at All Saints is the "coming out" of the parish. This was manifested in the hiring of an openly gay male rector. The people of All Saints came to value honesty in their life with AIDS, and this appreciation is reflected not only in the hiring of Father Schmidt, but also in the parish's embrace of his life partner, in the way the parish conducted funerals, and in the willingness of the parish to bless same-sex unions. Further, the parish is a place where her gay and lesbian members report that the "welcoming love of God is extended to them without conflict or ambivalence."<sup>50</sup>
- Members of the parish have reported that their experience with AIDS and AIDS loss deepened their personal prayer life and the liturgical life of the parish. They have come to experience the liturgy as an arena in which the concrete love of God is acted out. The intercessory prayers, in particular, served as an important source of support to many whose friends and loved ones were living and dying with AIDS.
- AIDS led to a flourishing of pastoral ministry and mutual ministry that helped to ease the pain of loss. Members drew closer together and particularly supported those among them who were called upon as caregivers.

### **Conclusion: The Future of All Saints**

As the people of All Saints face the future, the neighborhood around them is changing again. More families with young children are appearing on their doorstep. Paradoxically, it seems, the people of All Saints may now be called upon to extend their love increasingly to the very sorts of people who have not always welcomed and included *them* so readily in the past. Will All Saints' hospitality engage this new constituency? Are the members able to embrace not only the marginalized, but also the mainstream and

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<sup>50</sup> Manning, group interview, 25 April 2000.

increasingly prosperous young who inhabit the Haight? What about those who have not experienced the AIDS loss that was so much a part of their history? How will the members and leaders of All Saints share their stories and memories with newcomers who might be quite unaware of the pain they have known?

These are the challenges that face the people of All Saints as they look toward the future. Yet another challenge is finding a way to share the wisdom they have gained through their life with AIDS with many in the Bay Area and beyond who continue to face its ravages. How can they draw on their experience as a force for change in the community, the wider church and the world?

The people of All Saints have not experienced an AIDS loss in their parish since 1997. With the threat of AIDS removed from their doorstep, it may be tempting for parishioners simply to forget, to give thanks for their good fortune and to return to “business as usual.” However, as they move forward, they may choose to consider how they may yet share the fruits of their experience with others. Perhaps the wisdom they have gained may be put to use in the service of a direct outreach to those living with AIDS -- alternatively, new forms of outreach quite unrelated to AIDS may arise to engage their energy and new found wisdom

Whatever form their future ministry may take, the life of the parish has been influenced indelibly by the AIDS epidemic. In the next section, we shall explore how the theology and spirituality of All Saints, in conversation with the work of Julian, may inform pastoral praxis in situations of multiple loss and in AIDS loss, in particular.

Finally, we shall consider the implications of these theologies and spiritualities for the nature of the world we are called to create through socio-political intervention and pastoral praxis.

## EPILOGUE PART III

### REFLECTIONS FROM CONGREGATIONAL PRAXIS TOWARD EMANCIPATORY PRAXIS

The purpose of this section is to identify parallels, possibilities and problems as we consider the materials from All Saints in relationship to Julian's theology and in preparation for the more extensive critical conversation, constructive work and praxis proposals that lie ahead.

#### Parallels

The first striking parallel between Julian's experience and that of All Saints is the power of a transcendent experience to effect healing. Both Julian's vision and Kenneth Schmidt's deathbed encounter with Stephen Wilson were experiences in which these individuals were drawn beyond the limits of themselves and the world as they had known them. These experiences represent prototypes for the ways in which an encounter with Divine grace has the power to effect transformation. Besides experiencing transcendence through visions and relationships, transcendence may also be experienced in community fellowship, in caregiving, in worship and prayer and through the arts, as the interviews with All Saints' parishioners' attest. These experiences of transcendence offered great power for healing.

The second parallel is the centrality of love to the process of healing from traumatic loss. Julian's healing vision was a dramatic encounter with a God of love. In a similar way, Kenneth Schmidt's conversion experience with Stephen Wilson provides an example of how a profound experience of love creates a potent opportunity for resurrection even in the midst of loss. The love of an entire community can also generate

invaluable healing and support, as we have heard from the parishioners of All Saints.

The experience of love at the heart of transcendence appears to be central in effecting the healing that is achieved.

The third important parallel arises from the understanding that focusing on human worth and dignity, rather than on human sin, provides an important resource for recovery. Julian's positive anthropology contrasts with the pessimistic view of human nature prevalent in much plague theology. Likewise, Lucinda's experience of adopting a non-judgmental stance towards persons with AIDS as a result of her participation in the funeral liturgies provides an excellent example of the healing power of acceptance.

### **Possibilities**

Our study of All Saints has suggested a number of possibilities to consider in formulating an emancipatory praxis. First, we have learned how the approach of death sometimes creates possibilities for "extraordinary" pastoral care, as pastors may experience transcendent encounters with parishioners. Father Schmidt's deathbed encounter with Stephen Wilson provides an example of how this pastor went beyond normal boundaries of care in the service of love. The loving way in which All Saints pastors coped with end of life issues provides another example of how pastors are sometimes called to go beyond their comfort zone as death approaches. What makes such transcendent care possible is the pastor and parishioner's assurance that a loving God sustains them. For example, Lloyd Prator described what it was like for him to sit for hours with a parishioner who unsuccessfully attempted an overdose. He said:

you asked me what it was like to sit that night with Art and . . . ,  
I guess what I was thinking as I sat there and watched him take and then  
regurgitate and regurgitate all those pills was . . . "Well, he's doing the

wrong thing. I'm sorry he's doing this, this is a bad thing for him to do, but, on the other hand, I know that he's going to a God that he now understands better than he ever understood [God] in his life. That I [was] asked to be a part of this was a great gift."<sup>1</sup>

What made it possible for Prator to sit with this parishioner whose actions he questioned was the belief that a loving God sustained them both.

Second, the experience of All Saints testifies to the healing power present in a holistic environment. In creating a healing atmosphere, the people of All Saints have drawn on the power of sight, smell, taste, and hearing through their sacramental and liturgical practices. They have also created sacred spaces and times for honoring their beloved dead through the construction of the AIDS garden and memorial and in the practice of sponsoring services of remembrance. This multi-sensory approach appears quite effective in supporting the resolution of grief.

Third, interviews with All Saints parishioners have also uncovered certain difficulties that must be addressed in pastoral praxis with survivors of AIDS loss. Pastors must find ways to help parishioners express their anger towards God and resolve the underlying feelings of sadness and depression that may lurk beneath this anger. Navigating through these difficult emotions was particularly difficult for male parishioners, especially those who experienced the greatest amount of AIDS loss.

Finally, understanding the cumulative nature of loss appears essential. In many cases, the overshadowing loss described by a particular All Saints parishioner was not an AIDS-related loss; however, with further probing, parishioners did come to understand how their experience of AIDS loss had affected either their experience or memory of this

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<sup>1</sup> Lloyd Prator, interview by author, 18 October 1999, Sacramento, tape recording.

overshadowing loss. Further, understanding the cumulative nature of loss helped parishioners to understand that the disproportionate weight certain losses assumed could be attributed to the power of cumulative loss. For example, one parishioner noted explicitly that the tremendous grief accompanying Stephen Wilson's death included grief for *all* of the AIDS losses the parish and its individual members had experienced to that point. It would be interesting to explore why some losses have more power to catalyze grief than others.

### **Problems**

In considering the effects of AIDS loss on the theology of All Saints, one perplexing result emerged. This result is the potential conflict that may exist between the notion of resurrection life and the understanding of eschatology articulated in this work. The theology of resurrection life at All Saints rightly points out the inextricable connection between justice and the new life that is lived following resurrection. Nevertheless, for some survivors, particularly HIV-positive survivors, the justice that may be achieved *in this life* does not appear to be sufficient to overcome the suffering associated with AIDS. Because of their uneasiness with the amount of suffering they have experienced and witnessed, these survivors look to immortal life as the place where the justice they desire may be found. In many ways, this solution is quite reminiscent of Julian's belief in the great deed by which God shall make all things well.<sup>2</sup> What is troubling in both cases is the lack of specificity in these theological solutions. On the one hand, the belief in an ultimate justice, achieved beyond this life, is consistent with human

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<sup>2</sup> See pp. 215-16 above.



limitations and an understanding of life's mystery. On the other hand, a too easy acceptance of this position can promote an unhealthy resignation to present injustice. Further, it relies on the power of God, rather than on humans working in concert with grace, to bring about the justice for which people long. These factors suggest the need to develop a theodicy and an eschatology that are empowering of human participation with the divine in effecting transformation of present injustice. Also, finding ways to address survivors' emotions of anger and grievance through love *now* may provide healing and pastoral empowerment for those seeking justice in this life. We noted in Chapter 2 above that churches, in particular, failed to communicate God's love and acceptance in the early days of AIDS. In moving forward, the church must confess its past failure and find ways to witness more powerfully to the love of God and God's creative presence amid present pain.

In light of this brief review of certain points of comparison, let us now turn to a more extended conversation between the theology and spirituality of Julian and All Saints. We shall explore further the possibilities this conversation offers for emancipatory praxis and for the development of a pastoral theology informed by the experience of multiple loss.

## **Part IV**

### **Correlation and Its Implications for Emancipatory Praxis**

## CHAPTER 9

### TOWARD A THEOLOGY AND SPIRITUALITY OF MULTIPLE LOSS: A CRITICAL CONVERSATION BETWEEN PAST AND PRESENT

The creative or historical approach [to historical knowledge] suggests that we may be transformed in the present by the imaginative use of tradition. In other words, insights into the past have value precisely to the degree that they dispose us to respond to God's self-communication in the present.<sup>1</sup>

The purpose of this chapter is twofold. The first is to summarize key aspects of the experience of multiple AIDS loss. This review shall lay the groundwork for our second task, namely, examining points of similarity and difference between the theology and spirituality of Julian and that of All Saints. This comparison will shed light, first, on AIDS loss and second, and more generally, on multiple loss. It will also lay the groundwork for a constructive theology and spirituality of *multiple loss* that will be articulated in the next chapter. In constructing this theology, we shall draw upon the understanding of the problem of AIDS loss elaborated in Part I through Part III of the present work and upon the critical conversation between the theology and spirituality of Julian and of All Saints.

The major thesis guiding this and subsequent chapters is the belief that multiple AIDS loss, and indeed all multiple loss, may best be understood as a form of trauma. In this chapter, we shall focus more specifically upon AIDS loss as one form of multiple loss, whereas in the next we shall more directly consider the value of interpreting multiple loss as a form of trauma. In light of the present research, we shall attempt to formulate a

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<sup>1</sup> Philip Sheldrake, *Spirituality and History: Questions of Interpretation and Method*, rev. ed. (Maryknoll, N.Y.: Orbis Books, 1995), 176.

constructive theological and spiritual response to multiple loss conceived of as trauma. The aim of this analytic and constructive work is attunement to God's self-communication within the context of traumatic loss, including AIDS loss. That is, we shall consider how God's love is present and redemptive even amid the pain of this experience.

### **AIDS Loss: Toward a Deeper Understanding of Multiple Loss**

The first step in the constructive work is to understand the problem of AIDS loss in its varied aspects. A second step is considering how understanding the nature of AIDS loss contributes to a deeper understanding of the unique character of multiple loss as a form of trauma. Drawing on the descriptive work in Parts I through III above, therefore, let us consider key findings regarding the nature of AIDS loss.

#### **Social and Political Aspects of AIDS Loss**

The following findings, described in Part I, are crucial to understanding these aspects of AIDS loss:

- AIDS loss is more common in marginalized groups. Those vulnerable within society are at greatest risk. The particular groups that are most vulnerable appear to vary by geographic region. For example, gay men are more vulnerable in San Francisco, whereas heterosexual men and women are more vulnerable in Africa. In general, gay men, intravenous drug users, people of color, women, the young, and the homeless appear to be particularly vulnerable to the ravages of AIDS.
- AIDS loss tends to devastate community structures as it disproportionately affects particular communities. For example, gay men in the United States have found their gay "families of choice" to be critically affected by AIDS loss.
- The risk of infection and loss are directly associated with poverty and militarization and inversely associated with the social conservatism of a society. Women lacking

literacy and self determination are at risk. Further, the incidence of infection tends to rise in societies experiencing rapid economic growth.

- Society's response to AIDS and AIDS loss, like the churches' response, has most often been one of denial and minimization.
- The incidence of AIDS and AIDS loss has been associated with considerable stigma, leading to decreased social support for the bereaved. Further, because the groups affected by AIDS and AIDS loss are marginalized, mourners do not always have good access to the supportive social structures usually available to mitigate grief.

Consideration of the social and political aspects of AIDS loss, therefore, highlights the stigmatization and marginalization associated with it, the ways in which these social factors heighten the pain of loss, the enhancement of this pain through poverty and oppression, and the intensification of bereavement resulting from the community-wide devastation AIDS has wrought. These social and political factors clearly contribute to the perception of multiple AIDS loss as traumatic.

#### Psychological Aspects of AIDS Loss

Our review of the psychological literature on AIDS loss in Chapter 3 suggests the crucial importance of the following findings:

- AIDS bereavement frequently assaults the world view of mourners.
- AIDS loss overwhelms the young as it is an "off time" loss. "Off time" losses include losses that are inevitable and associated with certain life stages but occur at earlier or later stages than expected. An example of an off time loss is the death of a spouse at a young age.<sup>2</sup> Many young people have experienced a magnitude of loss from AIDS that is more normally encountered in old age.
- Important individual differences may mediate the response to AIDS loss. These may be associated with the "style" of an individual's response to loss, such as Schwartzberg describes, or variations in bereavement burdens or coping style of the sort described by Goldblum and Erickson.

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<sup>2</sup> I first encountered this term in Shrader's dissertation. See Shrader, "Descriptive Study of the Effects of Continuous Multiple AIDS-related Loss," 17. Shrader attributes this term to Patricia Weenolsen in *Transcendence of Loss over the Life Span* (New York: Hemisphere, 1989).

- Mourners of AIDS losses may vacillate between cognitive intrusion and psychic numbing.
- HIV-negative individuals may suffer significant survivor guilt in the wake of their diagnosis and have less access to emotional support for coping with these troubling feelings than HIV-positive individuals in the same social groups.
- Because many AIDS mourners experience great numbers of deaths and many and varied losses associated with them, AIDS loss provides a pre-eminent example of multiple loss.
- AIDS loss may also be understood as traumatic loss: as such, mourners may manifest a death imprint, death guilt, psychic numbing, counterfeit nurturance and efforts at formulation.
- AIDS mourners in heavily impacted communities may have an impaired sense of identity and question whether nature is trustworthy.
- Professional and non-professional caregivers, such as therapists, physicians, chaplains and buddies, working with AIDS mourners may suffer from secondary traumatic stress.
- AIDS loss may be accompanied by other psychological impairments, including depressive and anxiety disorders. These will require treatment in their own right.
- Particular bereavement burdens or impediments to coping may challenge mourners in their attempts to heal. The former include factors that may intensify grief, including being a parent, a caregiver or an HIV-positive individual; the latter include factors that may interfere with the ability to grieve, such as substance abuse.

Taken as a whole, the psychological literature on AIDS loss highlights two key aspects of this loss: the value of viewing AIDS loss as *multiple* loss and *traumatic* loss. The interpretation of AIDS loss as multiple loss arises from the concentration of AIDS losses in particular communities and from the great variety of losses mourners sustain with AIDS loss. The interpretation of AIDS loss as trauma rests upon several important factors. First, the psychological characteristics of AIDS mourners parallel those of

trauma survivors. Second, the community devastation associated with AIDS and its effects compares with the effects of other community-wide trauma such as those associated with natural disasters. Third, particular aspects of AIDS loss, including the prematurity of death associated with it, the protracted nature of the disease process, the great quantity of loss it has wrought, and the cumulative toll of the many and varied losses associated with it help to highlight its character as traumatic loss.

### Theological and Spiritual Aspects of AIDS Loss

Review of the literature in Chapters 3 and 4 and the field research and interview data described in Chapters 7 and 8 points up a number of key findings in these areas:

- The experience of AIDS loss may challenge the core religious beliefs and practices of mourners.
- The response of the Christian churches to AIDS loss was delayed and inadequate. Six factors, in particular, were responsible for this response. They included homophobia, fear of the drug culture, racism, works righteousness, fear of death and fear of sexuality.
- Because they associate sin with sexuality and drug use, churches may further stigmatize members of marginalized groups living with HIV and AIDS.
- The experience of AIDS loss may precipitate a spiritual search in mourners whose core beliefs are inadequate to the challenges posed by multiple AIDS-related loss.
- Believers who are unable to express their anger toward the Divine may experience frustration and arrested spiritual development. Feelings of anger may cover deeper feelings of sadness and depression.
- Some gay and lesbian people have experienced a blossoming of their spirituality as a result of life with HIV/AIDS.
- Healing from multiple AIDS loss may result from a profound encounter with love.

- Multiple AIDS loss may result in a deepened experience of community with others.<sup>3</sup>

Review of the religious and spiritual aspects of AIDS loss, therefore, points out the intense impact this loss may have on the worldview of mourners, the difficulties mourners may experience in relating to the institutional church, and the need to work through difficult and painful feelings in resolving the religious and spiritual upset associated with AIDS loss. Fortunately, experiences of love and healing amid loss may provide both hope and healing.

In summary, as this review clearly indicates, AIDS loss is an intense and devastating form of loss that exerts wide-ranging effects upon individuals, communities and society at large. This summary clearly highlights the complex nature of AIDS loss in its own right. Another surprising finding of this research, however, was discovering significant parallels between AIDS loss and plague loss that derive from their character as multiple and traumatic forms of loss. Before developing a constructive theology of multiple loss, therefore, let us consider parallels and differences between the experience of AIDS and plague loss and of the theologies and spiritualities associated with them.

### **Comparisons of AIDS Loss and Plague Loss**

As you may recall, I anticipated that exploration and analysis of the multiple loss associated with the Black Death and Julian's psychology and theology might help to shed light on the experience of AIDS loss. It was my hope that exploring a significant

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<sup>3</sup> I hypothesize that this phenomenon may be a consequence of the destruction of the belief in "personal specialness." The psychiatrist, Irvin Yalom hypothesizes that this belief underlies the denial of death. It may be greatly undermined in the face of the multiple loss AIDS represents. With the death of this belief, the individual may be more free to experience communion with other mourners. See Irvin D. Yalom, *Existential Psychotherapy* (New York: Basic Books, 1980), 117-29, 152-53.



experience of multiple loss rooted in another culture might highlight common features of the experience of multiple loss, clarify important cultural aspects of the experience of multiple loss, suggest psychological and theological themes to which to attend and place unique aspects of AIDS-related loss in relief.

### Similarities between AIDS Loss and Plague Loss

Several fruits have emerged from this comparative study. *First, the overall similarities between the chroniclers' accounts of plague loss and the contemporary experience of multiple AIDS-related loss were quite impressive.* The parallels encompassed both psychological and social factors, such as abandonment of the sick and dying, apathy, stigmatization and violence in the wake of multiple loss, and the scapegoating of strangers, foreigners and other marginalized groups, including Jews in the fourteenth century and gays and lesbians in the twentieth century.

*Second, the analysis of the plague demonstrates the tendency for stricken societies to develop religious explanations for their loss when scientific explanations seem lacking or inadequate.* In both the Middle Ages and in AIDS, disastrous loss has been interpreted often, but not invariably, in terms of divine punishment and disapproval. The writings of Julian and life of All Saints demonstrate that this interpretation is not inevitable. We have noted how the interpretation of multiple loss as Divine disfavor was offered early in the AIDS epidemic when AIDS was described as God's punishment on gays. In the same way, social analysts in the Middle Ages described the Black Death as God's punishment for sin.

*Third, analyses of the Black Death and of AIDS have demonstrated the power of fear in undermining human compassion for the sick and dying.* In the Middle Ages, this led to the abandonment of the sick and dying, even by clergy and physicians. In our time, denial and minimization of the effects of AIDS by individuals and public officials have greatly increased the death toll from AIDS. Further, stigmatization of persons with AIDS has increased the suffering associated with this already difficult diagnosis. It has resulted, for example, in job discrimination, loss of insurance benefits, schooling, housing, and in social ostracism of the infected.

*Fourth, the analysis has also demonstrated the power of scapegoating and the potential for violence that lie close to the surface in the face of inexplicable loss.* This tendency was dramatically illustrated in the suspicion of outsiders, persecution of Jews and the self-imposed violence of the Flagellants in the Middle Ages. In our time, it has been manifest in discrimination experience by persons living with AIDS and in the effects of homophobia and racism in contributing to the minimization and denial of AIDS. The latter led to a significant delay in the political response to AIDS which placed many at increased risk of infection and death in the early days of the epidemic. Suspicion of outsiders in our time has affected immigration restrictions on persons with AIDS.

*Fifth, intercessory prayer and the adoption of saintly protectors appear to be important in both pandemics.* All Saints' devotion to St. Michael, developed at the height of the AIDS epidemic, provides an important contemporary example of the latter. Interceding to patron saints may be particularly effective when individuals either experience anger towards the divine or fear divine punishment. In addition, a number of individual interviewees described the importance of intercessory prayer in upholding

them emotionally and spiritually in times of loss. As interviewees noted, intercessory prayer provides a means of engaging the entire community on one's behalf, thus, it helps to decrease the pain of isolation that accompanies mourning.

*Finally, both pandemics demonstrate the risk of cynicism that may be directed toward the institutional church when its response to widespread suffering is considered inadequate.* Clergy fell greatly in esteem in the Middle Ages in the wake of the plague, as, unfortunately, many abandoned the souls in their care to save their own lives. In our time, many believers have been alienated by the Church's contribution to intolerance toward gays and lesbians, a stance they perceive as contributing to intolerance in the wider society. This sentiment was voiced most emphatically in the interviews by George MacKenzie, an HIV-positive man who has been among the most active public advocate for persons with AIDS.<sup>4</sup>

#### Differences between AIDS and Plague Loss

Besides these parallels between the response to the plague and to AIDS, some key differences have emerged. *First, AIDS has not been interpreted predominantly in apocalyptic terms*, despite the fact that it has been associated with widespread global suffering. *Second, the religious response to AIDS has been characterized by a greater degree of religious pluralism* than the response to the Black Death. Daniel Defert makes this point very eloquently:

The history of religions is one of constant interpretation of meaning and reinterpretation of events. Today no religion is in a position to offer a unique moral pronouncement regarding the world event which is the sudden appearance of AIDS. Each religion is tormented by this event, as are the believers of whatever faith who suffer through their flesh, their

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<sup>4</sup> See pg. 265.

sexuality, or their loved ones. . . . [P]luralistic voices . . . contribute to an elaboration of meaning.<sup>5</sup>

While the medieval synthesis was disintegrating towards the latter part of the fourteenth century, the greater uniformity of the religious response to The Black Death, at least in the Western world, differs dramatically from the greater variety of religious voices responding to the AIDS crisis in our time. The Roman Catholic Church dominated the medieval social, religion and political world to a degree unprecedented since that time, and its explanations for the plague were widely disseminated. In the twentieth century, AIDS is a global phenomenon. Many religious interpretations and responses to AIDS co-exist, and believers and non-believers alike must struggle with these competing interpretations.<sup>6</sup>

*Another key difference between the religious understandings of AIDS in the medieval period and in our own time rests in the greater tendency today to emphasize the structural factors in society that relate to the spread of disease.* Explanations invoked for the plague, such as “punishment for sin” lent themselves to the condemnation of individuals. However, emerging responses to AIDS highlight the contribution of social factors in promoting the spread of disease. For example, the method of vulnerability analysis described in Chapter 2 highlights the role that particular social factors may play in placing marginalized individuals at increased risk. Further, theological explanations highlighting the structural nature of sin have much to offer in the analysis of the social

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<sup>5</sup> Daniel Defert, “AIDS as a Challenge to Religion,” in Mann and Tarantola, *AIDS in the World, II*.

<sup>6</sup> See J. Gordon Melton, ed., *The Churches Speak on AIDS*, for the wealth of religious interpretations offered.

factors impacting the spread of HIV/AIDS.

**Parallels between Julian and All Saints' Theologies and Spiritualities**

A number of intriguing parallels emerged between Julian's theology and spirituality, developed in response to the plague, and the theology and spirituality articulated by the members of All Saints.

*First, both Julian and the members of All Saints attest to the healing power that accompanies a transcendent experience of love.* Through her vision, Julian came to understand God as a courteous and homely lover who accepted her totally with full knowledge of her strengths and limitations. As described in Chapter 6, this encounter healed Julian from grief and empowered her for the mission of sharing God's love with others through her counseling and writing.

The same dynamic was present at All Saints. Perhaps the most dramatic example was Kenneth Schmidt's deathbed exchange with Stephen Wilson. Other members of All Saints, however, described moments in which they experienced "courteous and homely" love profoundly. Those members who shared such stories seemed, in my observation, to have achieved the best resolution of their grief. Their grief was not erased -- they still missed their departed loved ones. At the same time, people who had a transcendent experience of love seemed to have more hope and a greater sense of meaning despite great loss.

*Second, both Julian's writing and the interviews at All Saints suggest that key fruits of the radical encounter with mortality in times of traumatic loss are greater self acceptance and acceptance of others.* These two phenomena seem to go hand-in-hand.

Lucinda's comments about how she had been moved to greater love of others and self through her participation in the funeral liturgies at All Saints provides evidence for the relationship between acceptance of self and others. Terry also reported that she came to love herself more as she incarnated God's love in her care for her friend, Luciano. Similarly, Julian, experiencing how much God loved her, was able to accept herself and to grow in love for her "even Christians," even to the extent of risking condemnation to share written accounts of her visionary experiences with them. She was also moved to consider the possibility of universal salvation through her vision, in which she was given no sight of purgatory or hell.

*Third, Julian's experience, in particular, demonstrates the healing that can be achieved when the religious imagination reworks traditional symbols in a holistic way in the context of the community.* Julian re-experienced Christ's crucifixion -- she saw Christ's suffering and felt compassion and pain as she observed his death. Further, she appropriated her vision with the help of her fellow Christians: for example, in describing it to a priest who visited her, she began to appreciate its full significance. In a similar way, services of remembrance at All Saints seem to provide a potent source of healing. Through the development of a special place of remembrance and through the reading of the names of their beloved dead, the notion of the communion of saints has grown in significance within this parish. Holding the service of remembrance in the context of the Eucharist powerfully brings together past, present and future, and departed loved ones seem, at times, to be tangibly present. I expect that the addition of the columbarium will only heighten this awareness of the communion between the living and dead in the months and years ahead.

*Finally, this research suggests that spiritual resolution of grief involves two movements, first, a movement toward self acceptance and second a movement toward self-transcendence. Julian's awareness that she was loved by God freed her from guilt and enabled her to reach out to others with greater conviction and joy. Likewise, those at All Saints who have effective ministries of caregiving and advocacy are those who appreciate and attend to their own emotional needs. It appears that the climate of honesty and authenticity at All Saints helped to promote both greater self acceptance and more genuine and satisfying self-transcendence.*

### **Distinctions between Julian and All Saints' Theologies and Spiritualities**

Although there are similarities between Julian's and All Saints' theologies and spiritualities, there are also some important differences between them. In evaluating these theologies, following David Tracy, I have asked, "What manner of being in the world does each describe?"<sup>7</sup>

*Analysis of the theology of Julian and All Saints suggests that different emphases characterize their approach to finding meaning in multiple loss. On the one hand, the central message of Julian is the oft quoted: "Sin is necessary but all will be well." On the other hand, the central message of All Saints can be described as: "Nothing can separate us from the love of God." At the heart of Julian's theology is a belief in the rightness of creation and in God's power to make all things well. At the heart of All Saints' theology is the belief that God is present in every experience of life, including the terrible pain and loss of AIDS.*

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<sup>7</sup> Tracy, *Blessed Rage for Order*, 52.

*Second, these two core theologies are associated with slightly different understandings of the human condition.* Julian's central metaphor for human nature was blindness. She believed that we lack the ability in this life to see ourselves properly or to see and know God's love fully. In her view, we can become distracted by our own sinfulness and lose heart. The remedy is clear sight -- she obtained it in her vision, but she knew that her experience was exceptional. At the same time, she took pains to share the contents of her vision, because she believed that God wanted everyone to benefit from her experience. It was not meant for her alone!

All Saints' anthropology, in contrast, is grounded in an appreciation of alienation or abandonment as central to the human condition. The main question addressed by the parish's core theology, particularly the preached theology, is: Where is God? This suggests that a sense of God's absence is a great source of pain. The remedy for human pain proposed by the people of All Saints is discerning the presence of God. An awareness of God's presence amid pain is the primary means for overcoming the experiences of alienation and abandonment that accompany both oppression and life with HIV/AIDS.

It is important to note, however, that for a number of All Saints' men, in particular, the question: Who or What is God? is also profound. This question, articulated most often by the men I interviewed, has not always been answered to the satisfaction of parishioners. As noted in Chapter 7, some members have embarked on a wide ranging spiritual quest to obtain answers they find lacking within the All Saints' community.



*Third, besides these differences in core theologies and anthropologies, Julian and the people of All Saints differ in their approach to sin.* As noted in Chapter 6 and the Epilogue to Part Two above, Julian emphasizes a more individual notion of sin. Further, she appears to promote a satisfaction theory of the atonement. In contrast, while sin is not frequently discussed at All Saints, the members of the church do emphasize the notion of injustice. This emphasis is consistent with a structural understanding of sin. All Saints' theology of the atonement, expressed most clearly in the preaching, seems more akin to Abelard's. There is an emphasis in both the parish's preaching and prayer on the power of self-giving love to transform the world. This is expressed most directly in The Rev. Susan J. Singer's preaching. In her sermon based on the text, "Sir, we would see Jesus," she describes what we see in Jesus:

The Jesus we will see [in the Holy Week liturgies] is God being fully human, sharing with us in everything that it means to be human – including and especially in pain and betrayal and God-forsakenness and death.

When we see this Jesus, we see a whole new dimension of what God is like; we see a God who will be with us in everything, a God who is most with us when we lose our safe grip on our lives, a God who refuses to be separated from us even by death itself.

This is the glory of God that we see in Jesus. . . .

In Jesus we see the fullness of God's glory is to be found, not in the suffering and death themselves, but in the fact that God would choose to share them with us, to meet us in the worst that the world can do to us and to overcome those things on our behalf because God loves us. . . .

We have seen that Jesus and he has drawn us to himself.<sup>8</sup>

This excerpt helpfully summarizes the theology of presence and the understanding of

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<sup>8</sup> Sermon preached by Singer, 9 April 2000.

God's atoning love as experienced by the community of All Saints. It demonstrates an appreciation that God is with us in all aspects of life and the belief that, because God loves us enough to be with us always, there is nothing that can defeat the power of goodness and love.

*A final important difference between the spirituality of Julian and that of All Saints hinges on their approaches to eschatology.* Julian's emphasis on the great deed that shall make all things well represents an eschatology that is focused heavily in the future. This emphasis on the final great deed implies that humans must await God's action patiently as they suffer in the present. Thus, Julian emphasizes the notion of redemptive suffering. In contrast, I believe that the people of All Saints underscore the importance of God's action to bring about God's reign in the present. This is consistent with the priority they place on working for justice and inclusivity that was expressed most clearly in the survey results. Further, the interviews suggest an emphasis in their spirituality on living in the present and seeking God within it. Thus, All Saints' spirituality emphasizes discerning God's action in the present and cooperating with it, whereas Julian's emphasizes trust and longing for complete union with God in the future. On the whole, All Saints' emphasizes advocacy for justice above redemptive suffering. However, as we noted in the Epilogue to Part Three, the HIV-positive members of the parish, like Julian, look for ultimate resolution of injustice in the afterlife. This parallel suggests that those whose lives are most affected by the ravages of AIDS are more akin to Julian in their eschatology.

### **Toward A Theology and Spirituality of Multiple Loss**

As this review has indicated, the critical conversation between past and present has helped to identify key parallels and differences between AIDS and plague loss. Parallels include similarities in psychological, social *and* religious responses to multiple loss. Differences predominantly reflect the growth of globalization and pluralism. Perhaps the most striking finding, however, is the traumatic nature of multiple loss in both periods and the intensity of dis-ease it generated in individuals and societies.

Consideration of theological and spiritual responses to AIDS and the plague reveal the centrality of love in healing. Further, breathing new life into traditional symbols occurred in both pandemics and it was a source of relief and renewal. Differences in response are, in part, a matter of emphasis. All Saints' theology emphasizes the centrality of working for justice and of discerning God's presence in the present situation. Julian's theology, in contrast, emphasizes observing the efficacy of creation and redemption, living in longing and trust, and awaiting the great deed that shall make all things well.

Having explored the similarities and differences between Julian and All Saints' theologies and spiritualities, let us now explore understandings of trauma arising from the social scientific literature. This literature may help to nuance our understanding of traumatic loss and propose important avenues for theological and spiritual reflection.

## CHAPTER 10

### THE CONTINUITY OF LIFE AND LOVE: THEMES FOR A CONSTRUCTIVE THEOLOGICAL AND SPIRITUAL RESPONSE TO TRAUMATIC LOSS

Thus was I taught that love was our Lord's meaning. And I saw full surely in this and in all[,] that before God made us, he loved us; which love was never slaked, nor never shall be.

And in this love he has done all his work; and in this love he has made all things profitable to us; and in this love *our life is everlastingly fixed*.<sup>1</sup>

In every age man faces a pervasive theme which defies his engagement and yet must be engaged. In Freud's day it was sexuality and moralism. Now it is unlimited technological violence and absurd death. We do well to name the threat and to analyze its components. But our need is to go further, to create new psychic and social forms to enable us to reclaim not only our technologies, but our very imaginations, *in the service of the continuity of life*.<sup>2</sup>

In his book, *Multiple AIDS-Related Loss: A Handbook for Understanding and Surviving a Perpetual Fall*, psychologist David Nord describes multiple AIDS loss as a form of trauma. A psychologist colleague of his stated that, "the traumatic effects of AIDS-related loss are usually ignored. [Survivors of multiple AIDS loss] have suffered trauma and show symptoms of [post-traumatic stress disorder] but hardly anyone has recognized it."<sup>3</sup> The first purpose of this chapter is to develop an understanding of AIDS-related multiple loss *and* plague loss as a form of trauma. Then, in an attempt to enhance the conversation between the human experience of multiple loss and the Christian

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<sup>1</sup> Julian of Norwich, *Revelation of Love*, chap. 86, pp. 181-82 (emphasis mine).

<sup>2</sup> Lifton, *Death in Life*, 541 (emphasis mine).

<sup>3</sup> Nord, *Multiple AIDS-Related Loss*, 129. He attributes this quotation to his colleague, C. Tollfree.

response to it, I shall consider how psychological theories of trauma may provide helpful input to theologians attempting to understand, interpret and address the nature of multiple loss. Finally, I shall propose critical themes for a constructive theology and spirituality of multiple loss.

### **Understanding Multiple Loss as Trauma**

According to Nord, the psychological understanding of trauma emphasizes an event as traumatic if “it is something outside the normal range of human experience.”<sup>4</sup> He notes further that traumatic experience produces lasting injury to the survivor whose symptoms tend to cluster in three categories. First, survivors tend persistently to avoid stimuli associated with the trauma or to experience generalized psychic numbing. Second, they experience recurrent distressful memories associated with the traumatic event and third, they suffer from persistent symptoms of increased arousal.<sup>5</sup>

Review of research on both plague loss and multiple AIDS loss has highlighted ways in which these forms of loss may be understood as being outside the normal range of human experience. Both forms of loss were of overwhelming magnitude, both resulted in premature death, and both may be characterized, in Lifton’s terms, as grotesque and absurd. The abhorrent nature of the physical symptoms associated with these illnesses, the stigmatization that sufferers and their survivors endured, the vivid nature of the death imprint they imposed, and the degree of psychic numbing and avoidance they produced in survivors support the characterization of these forms of multiple loss as trauma.

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<sup>4</sup>Ibid., 130.

<sup>5</sup>Ibid.

## **Psychological Theories of Trauma and Their Usefulness for Theologians**

The purpose of this section is to explore how psychological theories of trauma may provide helpful input to theologians attempting to understand, interpret, and address the nature of multiple loss. As you may recall from Chapter 1, consideration of such theories is crucial to the critical correlational method which attempts to correlate the questions and answers arising from the human experience of loss with the questions and answers arising from the Christian tradition.<sup>6</sup> In analyzing the experience of trauma and the questions and answers provided by psychological analysis, we shall consider three different approaches: Ronnie Janoff-Bulman's Theory of the Shattering of the Assumptive World View, I. Lisa McCann and Laurie Ann Pearlman's Constructivist Self Development Theory and Robert Jay Lifton's Symbolization Theory of Trauma. When reviewing each theory, we shall also consider the theological implications embedded within it.

### **Janoff-Bulman and the Shattering of the Assumptive World View**

The first theory we shall consider applies a cognitive approach to the effects of trauma. Psychologists Ronnie Janoff-Bulman and Irene Hanson Frieze note that most people create life's meaning by relying on three major assumptions about the world. The first is a belief in personal invulnerability. The second is the view that the world is meaningful and comprehensible. The third is the assumption of a positive self-perception. According to Janoff-Bulman and Frieze, one of the most disturbing aspects of trauma is that it shatters these basic assumptions that people hold about themselves and

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<sup>6</sup> See p. 27 above.

their world. The consequence is a sense of “threat, danger, insecurity and self-questioning.”<sup>7</sup>

The first assumption, a belief in personal invulnerability, reflects the fact that people overestimate the likelihood of experiencing positive outcomes in life and underestimate the likelihood of experiencing negative events. Unfortunately, the experience of traumatization assaults this assumption and the most common fear of survivors is of recurrence of the trauma. Those who have been traumatized no longer “perceive themselves as safe and secure in a benign environment.”<sup>8</sup> The interviews suggest that the infection of the first All Saints parishioner shattered the assumption of invulnerability in the parish. Parishioners began to believe that they, also, could become infected and for some people, this shift resulted in an enormous fear of contracting HIV.

The second assumption described by Janoff-Bulman and Frieze is the assumption that the world is comprehensible and orderly. This assumption rests, first, upon a belief in justice -- we believe that people get what they deserve and deserve what they get. The second aspect of this assumption is a belief in personal control. By living cautiously, people often believe that they have some power to control whether bad things happen to them. Once again, the experience of HIV disease undermines each of these assumptions. People became infected without any knowledge of the possibility of infection; further, among those who became infected were some who had taken no known risks. An example of the latter would be a monogamous partner whose lover, unbeknownst to him

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<sup>7</sup> Ronnie Janoff-Bulman and Irene Hanson Frieze, “A Theoretical Perspective for Understanding Reactions to Victimization,” *Journal of Social Issues* 39, no. 2 (1983): 3.

<sup>8</sup> *Ibid.*, 5.

or her, was having an affair.

The last assumption is a positive self-perception. Most people tend to assume that they are worthy and decent people. When they experience trauma, however, many call this belief into question and begin to wonder if they have somehow “deserved” their fate. They may feel powerless, helpless or deviant as a result of their traumatic experience. The psychological dynamics of survivor guilt and counterfeit nurturance attest to the presence of these feelings in survivors. The interviews revealed that several members of All Saints continue to blame themselves for failing to respond adequately to those in the parish who were sick and dying with AIDS during the height of the epidemic. The helplessness they felt then and the guilt they feel now have undermined their positive self-perceptions.

Of course, each of these assumptions affects one’s theology. The first assumption of personal invulnerability taken to an extreme, causes us to see ourselves as gods rather than as creatures. The second assumption in its extreme form leads to a rigid expectation of justice rather than a reliance on grace. The third assumption undermines the view of individuals as created in God’s image and as capable of experiencing forgiveness. Janoff-Bulman’s work is helpful in the theological consideration of AIDS loss, for extrapolation from it in the manner I have illustrated points out key beliefs that may need to be addressed in developing a theology of traumatic AIDS loss.

#### McCann and Pearlman’s Constructivist Self Development Theory

A second helpful psychological approach arising from the social scientific literature on trauma derives from the work of I. Lisa McCann and Laurie Ann Pearlman. In their comprehensive theory of psychological trauma, these psychologists describe the



importance of trauma in disrupting key cognitive schemas through which people tend to understand their basic needs. McCann and Pearlman hypothesize that “trauma disrupts one’s central needs and alters, disrupts or disconfirms one’s beliefs, assumptions and expectations in those central needs areas.”<sup>9</sup> McCann and Pearlman describe seven schemas, related to central needs, that may be disrupted by trauma.:

- *Frame of reference*: This tends to be an overarching schema, and they say it is comparable to Janoff-Bulman’s assumption of a meaningful world. It consists of three separate orientations: attributions of causality (whether a person blames his or her character or behavior for misfortune), schemas related to hope (optimism about the future, trust in the world), and locus of control (whether an individual looks to internal or external sources for positive reinforcement.) They suggest that the experience of trauma may cause a shift in the latter schema from one mode to the other.
- *Safety*: This schema refers to the illusion of safety that allows individuals to feel capable of protecting themselves from danger and harm in a world that is potentially dangerous and unpredictable. Many individuals form “rules of safety” to protect themselves from harm, and the disruption of these by trauma may lead to “anxiety and startle reactions, avoidant or phobic reactions, physiological hyperarousal to trauma-related stimuli, nightmares, intrusive recollections of the threat, and intense fears about future revictimization.”<sup>10</sup>
- *Trust/dependency*: There are several components to this schema: the need for support from others, the expectancy that others can be relied upon to provide this support, and the ability to trust in one’s own perceptions and judgments.
- *Independence*: This schema refers to the need to control one’s own rewards and punishments or to be in control of one’s behavior and destiny. It refers to the need to believe in oneself versus to doubt oneself.
- *Power*: This schema is the need to exert control over one’s environment. It includes the ability to protect one’s body and personal space from dominance by others.

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<sup>9</sup> I. Lisa McCann and Laurie Ann Pearlman, *Psychological Trauma and the Adult Survivor: Theory, Therapy, and Transformation*. Brunner/Mazel Psychosocial Stress Series, no. 21, New York: Brunner/Mazel, 1990), 61.

<sup>10</sup> Ibid., 67.

- *Esteem*: This schema refers to the belief in one's own worth and value. It includes valuing oneself, understanding and knowing oneself, enjoying the experience of relating to oneself and enjoying hope and faith in oneself.
- *Intimacy*: This schema refers to the desire for belonging or connectedness with other human beings. Violation of this schema through trauma may result in a sense of isolation or alienation and undermine one's sense of belonging in the world.

McCann and Pearlman's theory is helpful in its sensitivity to individual differences. They note, for example, that schemas develop in a unique personal history and it is this history that shapes the way that persons respond to trauma. Sometimes, persons experience trauma as confirming negative schemas. At other times, the traumatic event disrupts previously positive schemas. To understand fully the effect of trauma on a particular individual, they note that it is important to explore the complex relation among life experiences, schemas and psychological adaptation within the context of a person's social and cultural environment.

McCann and Pearlman refer explicitly to the role of spirituality in recovery from trauma, and their experience in this area can be particularly helpful to our constructive efforts. They note, first, that many people re-evaluate their spiritual beliefs in the wake of trauma. They state, second, that spiritual beliefs are particularly significant to the frame of reference, and that these beliefs are particularly vulnerable to disruption after traumatization. Experiencing trauma causes people to question their beliefs about God and about themselves. Frequently, people ask themselves, "Why? Why has God allowed this to happen?"

Given such questions, the usefulness of McCann and Pearlman's theory lies in the way it enables more precise analysis of the meaningless and emptiness that clients often experience following traumatic loss. Their theory predicts that the dis-ease

accompanying trauma may result for a number of reasons. For example, clients may feel abandoned by God, they may feel such degree of guilt that they think God can never forgive them, they may feel unsafe and the sense that God will no longer protect them, or they may experience a disruption of their self-esteem or of intimacy in their relationship with God. Application of this theory thus allows caregivers to make more exact assessments of the spiritual and theological disruptions that survivors are experiencing. Finally, McCann and Pearlman also emphasize the role that spirituality may play in bringing about healing from trauma.

McCann and Pearlman's theory, like Janoff-Bulman and Frieze's, points out the need to attend to the varying ways in which trauma may interact with a person's psychological and theological understanding. At their core, the schemas identified by McCann and Pearlman seem to address the power of God, the power of individuals, the individual's self-worth and the nature of a person's relationship with God and others.

#### Lifton's Symbolization Theory of Trauma

The final helpful social scientific work related to trauma is, of course, the work of Robert Lifton. In contrast to the theories addressing cognitive concerns, Lifton's theories address how trauma disrupts primary symbols, including symbols of life and death.

In a helpful summary of his work, Lifton describes ten principles that appear to be central to understanding survivors of trauma. He includes in his framework:

- The principle of *being a survivor*. In Lifton's view, dealing with trauma begins with the recognition that in the most artificial and harmful way the issue of death has been omitted from treatments of post-traumatic stress. The issue of death is central conceptually and in every other way and must be acknowledged in theory and treatment.

- Second, we must acknowledge that *survival is an achievement*. The survivor can choose to remain locked in numbing or use the survival as a source of insight and growth
- The third principle lifts up *the human connectedness of survivors*. Lifton describes this as the ultimate dimension of trauma. The ability to symbolize immortality is key to recovery. Immortality may be symbolized through one's children, works, influences, nature, a spiritual principle or through experiences of transcendence. One of the most devastating aspects of trauma is the way that it can lead to dissociation and discontinuity in experience, thus disrupting a sense of connectedness.
- The fourth principle is that *post-traumatic stress disorder is a normal reaction to extreme stress*.
- The fifth principle acknowledges that self-condemnation is the source of psychological guilt in survivors. This guilt is associated with *failed enactment*.
- The sixth principle refers to *emotional vitality*: survivors must choose between feeling and not feeling.
- The seventh principle identifies *psychic numbing as the source of discontinuity in the self*. According to Lifton, the mind needs the nourishment provided by the continuous process of creating images to be healthy. This capacity for forming images is impeded by psychic numbing.
- The eighth principle affirms *the survivor's search for meaning*. Lifton says that scientists must find a way of addressing the idea of meaning, because without addressing this issue, they cannot address post traumatic stress.
- The ninth principle names *the moral dilemmas of trauma*. In Lifton's view, we must both legitimize the right of survivors to have symptoms like war neurosis, at the same time as we render illegitimate some of the destructive or traumatic situations that create the painful symptoms they experience.<sup>11</sup>
- The final principle relates to the *transformation of the self*. Lifton emphasizes the unity of the self in his theoretical formulations. This emphasis better allows us to see the dialectical nature of survivors who struggle, on the one

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<sup>11</sup> Lifton defines war neurosis as a refusal to die coupled with a refusal to kill. It was exemplified in a soldier at My Lai who kept his gun faced to the ground. He notes that this double refusal was the beginning of wisdom for many Vietnam veterans. See Robert Jay Lifton, "Understanding the Traumatized Self: Imagery, Symbolization and Transformation," in *Human Adaptation to Extreme Stress: From the Holocaust to Vietnam*, ed. John P. Wilson, Zev Harel, and Boaz Kahana. Plenum Series on Stress and Coping (New York: Plenum Press, 1988), 11.

hand, with the capacity for staying numb and on the other, with the capacity for symbolization and even for illumination with which they may be graced.<sup>12</sup>

Lifton's theories suggest the need to attend to several issues in developing a constructive theology and spirituality of AIDS. They include the need for a theology of death, a theology of community, a theology of forgiveness and a theology of human continuity. Lifton's work also suggests the importance of a spirituality of vitality and of a wholistic understanding of human anthropology.

In summary, therefore, consideration of social scientific theories of trauma suggests the need to attend to particular themes in the construction of a theology and spirituality of AIDS loss. These themes refer both to core beliefs, such as those described in Janoff-Bulman's assumptions and McCann and Pearlman's schemas, and to central images, such as images of continuity Lifton identifies, that may be assaulted through the experience of trauma. As we move toward the construction of a theology and spirituality of AIDS loss, we shall attempt to accent the beliefs and images that have proven important psychologically.

### **Toward A Constructive Theology and Spirituality of Multiple Loss**

The purpose of this section is to describe the key elements of a constructive theology and spirituality of multiple loss in general and AIDS loss in particular. In identifying these elements, I have drawn on the historical material, the study of All Saints and on the social scientific literature on traumatic loss.

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<sup>12</sup> A fuller description of each of these principles may be found in Lifton, "Understanding the Traumatized Self."

## The Nature of God

This description shall address two aspects of God that were important in this dissertation: understanding God as love and experiencing God as Trinity.

### God as Love

Understanding God as love appears very helpful in healing from traumatic loss. Perceiving God's loving nature was at the heart of Julian's vision. Encountering God's incarnate love was also central to healing from AIDS loss at All Saints. Parishioners experienced God's loving nature in two ways. First, some experienced the love of God either in or through the concrete care of community members. This experience was central both to Kenneth Schmidt's encounter with Stephen Wilson and to the support group's visit to Ken in the hospice. Second, some members describe a more "transcendent" experience of God's love in nature, in liturgy or in community.

The experience of God's love as described by our sources has certain properties: it is frequently surprising in its intensity, it is unbidden, and it leads to greater self-acceptance. It may best be described as a gift in that it is unanticipated, freely bestowed and delightful in its consequences.

Among the most inspiring passages in Julian's writings are those in which she attempts to communicate the nature of God's love. For example, Julian uses the image of God's love as clothing in attempting to describe its omnipresence:

[Christ] showed me further understanding of his homely love. I saw that he is the ground of all that is good and supporting for us. He is our clothing that lovingly wraps and fold us with such tender love; for truly he can never leave us. This made me see that he is for us everything that is good.<sup>13</sup>

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<sup>13</sup> Julian of Norwich, *Revelation of Love*, chap. 5, 8.

In Julian's view, therefore, God's love, undergirds our being and comprises all goodness.

In her famous description of creation as a hazelnut, Julian articulates the role of God's love in bringing all creation and us into being and in sustaining us in this life:

At the same time [as he showed me his love as clothing, Christ] showed me something small, about the size of a hazelnut, that seemed to lie in the palm of my hand as round as a tiny ball. I tried to understand the sight of it, wondering what it could possibly mean. The answer came: 'This is all that is made.' I felt it was so small that it could easily fade to nothing; but again I was told; 'This lasts and will go on lasting forever because God loves it. And so it is with every being that God loves.'<sup>14</sup>

According to Julian, therefore, God's love is responsible for our being and our preservation.

The images of God's love which Julian offers are notable for the great value they place on individual life. Julian's communication that each person is intentionally created, is loved and valuable and is redeemed through Christ's suffering may provide a powerful form of healing in situations of traumatic loss. In situations of massive death, individuals may come to feel as though human life and their life in particular lack value, meaning and purpose. For this reason, the description of God's personal and tender love that Julian provides may be an important resource for healing in such circumstances.

Understanding God as love provides a criterion for seeking God's presence amid the epidemic. The cipher at All Saints is: where love is, God is.

Further research is needed to explain exactly how love is perceived to yield its healing effects. Both Julian's writing and the experience of interviewees at All Saints

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<sup>14</sup> Ibid.

suggests that love effects healing through creating an increased capacity for self acceptance. The present research, however, does not help to explain why some people, particularly the women at All Saints, experienced God's love more clearly within the epidemic, while others, particularly the men of the parish, experienced a sense of greater distance from God. The research does suggest that there is an important relationship between anger and alienation, since men who had experienced greater loss seemed also to experience greater distance from God. Attending to factors that heal these feelings of anger and alienation from God will be important to future research on AIDS loss.

Further, as this research suggests, understanding God's nature as love does not remove all the questions that arise in situations of multiple loss. It does not, for example, provide a way of understanding why God allows suffering to exist. The present study can only describe how some people are able to find meaning and comfort amid suffering. It does suggest, however, that to the extent that we cultivate the capacity to be loving, the amount of suffering associated with AIDS will be reduced. As we have observed, among the greatest burdens of suffering with AIDS and the plague were the terrible burdens of stigma and intolerance too frequently imposed on those who lived with it and those targeted as responsible for its spread. Perhaps we may become agents of healing amid loss to the degree that we are able to incarnate the love of God that is described so clearly and imaginatively by Julian and the people of All Saints.

#### God as Trinity

The nature of God as Trinity also offers great promise in the area of AIDS loss. The notion of diversity within the Godhead central to Trinitarian theology promises great potential for embracing the varied constituencies in our world who live and die with



AIDS. As noted in Chapters 2 and 5, suspicion of difference and scapegoating of those who embody it were causes of extreme suffering both in the AIDS epidemic and in the Black Death. A trinitarian notion of the divine celebrates diversity, and thus provide a theological rationale for embracing difference.

Second, the notion of God as community embodied within the concept of the Trinity provides a basis for the connectedness that Lifton has articulated as key to the survivor's search for meaning. In fact, the understanding of Trinitarian relations as a paradigm for human friendship suggests that the human potential for intimacy and community is grounded in the Godhead. The notion of this friendship as eternal provides a foundation for connection between the living and the departed whose friendship may be understood to endure beyond the confines of the present.

Images of God consistent with Trinitarian formulations were important to the people of All Saints Church. Particularly central were images of God as creator, liberator and comforter. These images describe three different ways of responding to the AIDS pandemic: as co-creators, we may work with God to effect healing. As liberators, we may share in Christ's work of redemption through working as agents for justice to address the forces of exclusion and oppression that have allowed AIDS to proliferate. Finally, as comforters, we may mirror the divine comfort that God extends to those who suffer.

Reflections on the Trinitarian nature of God are essential to Julian's work. It is through her understanding of the Trinity that Julian is able to emphasize the power of God's redemptive work and its manner of operation. Julian frequently describes the economy of salvation in threefold terms. She describes God in terms of might, power and wisdom; as maker, protector and lover; and as working through nature, mercy and grace.

Julian's understanding of the Trinity provides a resource for describing both the healing attributes of God and the way in which these attributes exert their effects. Perhaps the usefulness of these notions in the AIDS epidemic are the ways in which they increase the richness of our language for God and our appreciation of the varied ways in which healing can be effected.

In short, then, a theology of God in situations of multiple loss benefits from an understanding of God as loving and as Trinitarian. More work is needed to reveal why some survivors are able to experience and integrate these qualities of God in their concrete interactions and experiences, whereas others emerge from the experience of AIDS loss with more wholly transcendent notions of God.

#### Creation

One of the most compelling aspects of Julian's theology is her understanding of the efficacy of creation. This aspect of her vision inspires hope. At the same time, understanding creation as a work in process, rather than as an end result, seems more useful to twentieth century survivors. Efficacy is not always immediately evident in this century of death and destruction, and, for that reason, a theology of AIDS profits from an understanding of creation as ongoing and risky. For one thing, this understanding provides a basis for the existence of disease. Further, it profits from a view of human participation as co-creators with the divine. It is also consistent with the view that God continues to work to bring all things to fulfillment. In these ways, it is true to human experiences of limitation and productivity. We are familiar in our own creative activities with experiences of frustration and experiences of self-transcendence. We know ourselves, therefore, as limited *and* also capable of exceeding our limits through

inspiration. Perhaps this dual characterization is also true of divine creativity. If so, it frees people from having to choose between an all powerful God and a limited God. God, like us, is both powerful *and* limited and counts on the cooperation of all of creation's creatures in achieving good. A dynamic understanding of creation of this sort seems called for by the challenges of the AIDS crisis.

### Sin

Theology of multiple loss is informed by differences between Julian's theology and the theology of All Saints, as well as by similarities. This is particularly true for understanding sin. An emphasis on the structural aspects of sin seems most helpful in light of the challenges posed by AIDS. An understanding of sin as oppression accounts for much that is evil in the pandemic, including the vulnerability of the sick, the stigmatization and violence they experience and the inequalities in incidence and treatment that characterize the epidemic globally. I believe that Mary Elizabeth Moore's characterization of sin as refusing to receive gifts, as destroying and denying life and as thwarting chaos and creativity provides a helpful rubric for life with AIDS.<sup>15</sup> This understanding, derived from the analysis of sexism, captures some of the major dynamics of an epidemic in which too many lives have been viewed as expendable. Drawing on these understandings, I would propose that we are called in this pandemic to offer hospitality to those who seek prevention information, treatment and support; to embrace the diversity of those living with AIDS; and above all, to affirm life amid death and love in its multiplicity of forms.

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<sup>15</sup> See pg. 102 above.

### Immortality

The notion of immortality developed in response to AIDS must acknowledge the importance of human continuity. This emphasis is a major contribution of Robert Jay Lifton's work, for he clearly and repeatedly demonstrates the importance of the symbol of continuity to survivors. This affirmation of the power of continuity as a source of hope reveals the nature of hope as transcendent. Continuity may be found in all of the ways Lifton describes: through children or others in whose development one has invested, through one's creative work, nature, life lived in response to over-arching principles, such as a quest for justice, and an experience of transcendence. In Christian theology, these forms of continuity might be identified as forms of immortality.

The central Christian metaphor for immortality is the resurrection. We have already noted the importance of this concept to the people of All Saints and their understanding of resurrection as God's continual presence in every life event, including suffering and death. Lloyd Prator helpfully describes resurrection as a continual re-creation, a renewing power at the center of life. Resurrection may be understood variously, but central to each of the images we have highlighted is the notion of "continuity" that Lifton identifies.

The experience of All Saints also points to the power of memory as a sign of continuity. The interviews revealed the transforming power of dangerous memories and of the way in which memories of loved ones who have died from AIDS can fuel and undergird efforts to achieve the justice that was denied them while alive. Relying on memories as a basis for present advocacy provides a powerful form of continuity. All Saints' experience demonstrates that the sharing of memories can unite a community and

strengthen it as it experiences and recovers from loss. Remembrance is central to the Eucharistic piety of the parish, since anamnesis lies at the heart of the Eucharistic act. The appropriation of memory for transformation, central to Eucharistic theology, was amplified amid life with AIDS at All Saints. The experience of All Saints has provided tangible evidence for the power of memories to sustain, to heal and to encourage those experiencing loss. In sharing stories, sewing quilt squares and creating sacred places of memory, the parish expresses the core of the Eucharistic piety central to its life in creative and powerful ways.

### Human Nature

Experiences of multiple loss reveal both the strength and fragility of human nature. This two-fold aspect of human nature is just one of the many dichotomies revealed in loss. As Lifton notes, survivors struggle with conflicts between feeling and not feeling, remaining connected to others or living in anger and suspicion, and remaining connected to painful experiences or dissociating from them.

This understanding of the complexity of human nature is summarized in the theologies we are considering. For example, Julian provides a clear and helpful understanding of theological anthropology. Her two-fold understanding of human nature views people as bound by their frailty and empowered through likeness to God. This two-fold understanding captures well what Lifton has described as the duality of survivors who struggle both with defensive reactions against pain and a desire to embrace fully the transforming power of their experiences. Julian also provides a very helpful understanding of the way in which the potential for human wholeness emerges from the integration of our two-fold nature. This integration is made possible by the union of

substance and sensuality accomplished in the incarnation. In Julian's view, Christ's saving work on the cross heals the split between these two aspects of our nature that resulted from human sin.

This research has revealed the importance of forgiveness to survivors. The acknowledgment of human limitation, central to Julian's anthropology and to the spirituality of All Saints described in Chapter 8, is essential to the experience of forgiveness. People are creatures, valuable to the Creator and of infinite worth, but they also struggle with finitude. One of the graces that emerges in traumatic loss for some is the radical awareness of mortality -- as noted above, Irvin Yalom suggests that the awareness of limitation accompanying the integrated knowledge of death frees those experiencing it from the "myth of specialness."<sup>16</sup> Destruction of this myth in situations of multiple loss may create an increased capacity for communion among survivors and, paradoxically, provide a healthy means of transcending human limitations in the context of loss.

Unfortunately, as Lifton notes, too many survivors are crippled by guilt for what they were unable to achieve in the face of massive death. This finding occurred in the interviews with All Saints parishioners. James Pennebaker's work with holocaust survivors and others experiencing trauma describes the healing effects that can occur when survivors have opportunities to share their memories in writing and with empathetic listeners.<sup>17</sup> He discovered that such sharing led to decreased illness and improved

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<sup>16</sup> See this reference to Yalom's work on pg. 296 above.

<sup>17</sup> This research is described in James Pennebaker, *Opening Up* (New York: Morrow, 1990) 37-51 and 94-97.

immune function. This findings suggest that Christian communities may helpfully provide opportunities for sharing painful memories -- as survivors learn that others struggle with these same feelings, they may experience relief. Further, being able to share these painful memories and feelings *and* experience acceptance in the context of Christian community may create a tangible experience of God's love and forgiveness.

### Death

A theology of death is essential to the experience of multiple loss because the fear of death, normally repressed, breaks through with great forcefulness in epidemics and other disasters. Once again, Robert Jay Lifton helpfully captures the essence of the survivor's experience in pointing out the centrality of death to it. The fear of annihilation drives the survivor's attempts at self protection -- to fail to acknowledge that fact is to miss the central dynamic characterizing the survivor's psyche.

Death represents the ultimate insult to human existence. As such, it is to be feared. However, the literature on surviving trauma suggests that some things are as frightening and perhaps more frightening than death. The automaton-like life of survivors in the grip of psychic numbing may be one. The chronic sadness and depression that characterize the life of some AIDS survivors may be another. The experience of degradation resulting from homophobia or stigmatization of persons with AIDS is also very debilitating. In the face of such incapacitation, one aim of ministry with survivors and with those living with AIDS must be to create, as much as possible, the conditions that lead to the fullness of life described in the Gospel.

None of us knows for certain what lies beyond this life. As indicated in Chapter 4, Scripture offers images of everlasting life that provide comfort and hope to many

people. However, in keeping with Lifton's analysis, it may be more helpful in situations of multiple loss to emphasize the symbol "continuity of life" in the face of the death's certainty rather than "everlasting life." This emphasis *is* agnostic about the possibility of life after death. It affirms that *life* will continue, rather than that *a particular life* will continue. Nevertheless, this emphasis focuses on alleviating suffering and creating meaning in the present and projecting these activities into the future, rather than living for an unknowable future. The notion of continuity of life, therefore, suggests an ongoing trajectory of life rather than the discontinuity between "worldly life" and "everlasting life" that may be associated with more traditional notions of immortality. In keeping with Lifton's findings, affirming the continuity of life may be crucial in situations of massive death when many feel that life itself is dying.

In developing a theology of death, two emphases are important. The first emphasis is a way of thinking about death that allows people to *imagine* it -- to face it honestly in all of its destructiveness. The second requirement is a way of transcending death, of finding hope despite death's inevitability. A useful metaphor in the face of death is the paschal mystery: Jesus' crucifixion represented an undeniably difficult and painful death, yet despite this real death, everything that Jesus believed in and worked for lives on and continues to generate hope and meaning. These facts, taken together, testify that death is *an* end, but not *the* end. At All Saints, people who have died continue to exert a powerful influence on the life of the community and its members. To live life fully and lovingly as they did is a potent way of preparing for the inevitability of death. This manner of living may provide the best antidote to the fear of psychological destruction so central to the fear of death.



### Theological Reflection

Work with Julian and All Saints illuminates the nature of theological reflection. Both Julian's writings and the experience of parishioners suggests that theology may emerge from experiences of love that occur in the context of pain and loss. This research has demonstrated that experiences of love may be embodied and social and may draw on the imaginative and symbolic capacities of the soul. They may also have a transcendent dimension. In fact, the profound experiences of love amid loss described by Julian and the people of All Saints have, at times, exceeded the intense experiences of pain and loss in which they occurred. The effect of these profound encounters with love may be dramatic and life changing, or they may be more modest. Both Julian and the interviewees' experience suggest, however, that the fruits of a profound encounter with love amid loss are greater self acceptance and an increased capacity for self-transcendence.

Transcendent experiences of love may occur with greater frequency at the boundary between life and death, whether with death in its symbolic or literal forms. In encountering death, survivors may glimpse something "greater" than death itself, something of enduring value that infuses life with meaning. Those who have such experiences may become endowed with the "survivor missions" of which Lifton speaks. At the core of the experience of love is a vitality that "trumps" the meaninglessness death that the survivor of massive death both witnesses and is experiencing -- the power of love may infuse all of life, even the encounter with overwhelming death, with a deep meaning that overcomes the tendency to despair. Both Julian and the interviewees at All

Saints attest to the power of love in this way, and their encounters with it are very compelling, indeed.

The encounter with love that leads to theology is honest. It does not lead to the repression or annihilation of pain -- rather, it emerges with the full knowledge and expression of pain. Rather than denying pain, love embraces it and graces it and makes it possible for the reflective survivor to enliven and re-appropriate in the midst of it life-giving symbols that he or she may previously have discarded. Love has this effect through breathing new life into symbols. As these symbols come alive again in the heart and mind and in community, survivors are empowered to share the vital energies that lie at their core. In this manner, the Spirit brings life from death, and faith is renewed even in situations of the greatest extremity.

#### Spiritual Themes for Life Amid Multiple Loss

The purpose of this section is to highlight important themes for a constructive spirituality of multiple loss, particularly AIDS loss. As indicated in Chapters Four and Eight, the spiritual effects of multiple loss appear to include an increased capacity for self acceptance and self-transcendence. In Chapter 8, in particular, we noted the various ways in which these qualities were realized and expressed at All Saints. Self acceptance was manifested in survivors' willingness to accept the reality of vulnerability and the limited nature of human life, in an increased ability to live in the present, in gratitude for life, and in honesty. For example, Tom described how his increased awareness of death with AIDS reduced his own fear of death, Leona described her heightened awareness of the joy of living day by day in the face of an increasing number of losses, and Jerome described how All Saints' ability to accept honestly the reality of AIDS strengthened the whole

AIDS strengthened the whole church which grew in love and unity through its ministry of care. Self-transcendence was experienced in practices such as liturgy, prayer, engagement with the arts and work for justice. For example, All Saints' rich Anglo-Catholic liturgy, its beautiful AIDS memorial and annual AIDS services of remembrance fostered a sense of transcendence. These practices provided avenues for an encounter with a reality beyond the self that infused life with meaning and enlarged the circle of concern that can become restricted in grief.

In addition to these two themes, the importance of honesty and of vitality in situations of loss must also be stressed. A healthy spirituality requires an authentic and holistic climate – surely life with AIDS has made this clear! To the extent that people wall off aspects of experience, such as sexuality, or to exclude others, to that same extent shall they and the world suffer. AIDS has illustrated the dangers of hubris and the need to consider the fragility of human bodies and souls. Further, it has revealed through survivors the value of embracing life in the present moment in all of its fullness. As Jerome mentioned in his interview, life with AIDS “elevated everything to a new level . . . every person became more precious,” pain became more painful and joy more joyous. The fact that both love and life may be endowed with such deep meaning amid great loss is surely a sign of resurrection -- of the presence of God amid pain. It is that presence to which my studies have alerted me and I am grateful to Julian and to the people of All Saints for sharpening my awareness of its healing power.

### **The Continuity of Life and Love**

In conclusion, the review of psychological work on trauma illustrates the importance of attending to the beliefs and practices that are disrupted in traumatic loss. Key beliefs affected by trauma include beliefs about the trustworthiness of God and creation, the nature of justice, the importance of human worth, the role of the community, and concerns with personal and Divine power. Key practices disrupted by trauma include the development and appropriation of symbols adequate for interpreting and creating meaning in traumatic situations. A theology and spirituality developed in response to AIDS must attend to these beliefs and practices in offering hope and healing.

The greatest surprise arising from this research was the consistent theology of life and love that emerged in the lives of survivors. Julian and the people of All Saints were not destroyed by the significant trauma they had experienced -- instead, they were strengthened even amid their sorrow through an encounter with love that offered them genuine healing and acceptance. This experience of love was personal and transforming. Communicating its power became a priority for survivors such as Julian who longed to share with others the gifts of love she had received. The attempts to communicate the nature of love energize survivors, renew their sense of purpose and meaning, and encourage them in the creative task of formulation. Through the communication of their insights to others, survivors create a legacy of love that contributes to the renewal of life. Their enduring testimonies provide one more instance of the triumph of love over death and remain as beacons of hope for those who follow.

## CHAPTER 11

### WHAT KIND OF WORLD? TOWARD AN EMANCIPATORY PRAXIS OF CARE

What we may hear when we listen through pain is the promise of a presence that transcends our limited efforts at care. Human pastoral care is sustained by its participation in the healing care of God. Before God there are no hierarchies of difference; the ones giving care and those receiving care are all 'broken hearted,' women and men alike. What we hear when we listen is 'the voice of God as that voice speaks silently and mysteriously through all the other voices to which our ears give attention' and that voice invites our participation in making all things new.<sup>1</sup>

Having engaged in critical conversation between the past and present, we can now return to the question with which we began. What have we learned from our exploration of AIDS loss about the kind of world we are called to co-create? In this chapter, we shall first consider the kind of world in which the suffering of AIDS and AIDS loss may be alleviated. We shall then examine socio-political and pastoral strategies that offer promise in transforming local and global responses to AIDS. Finally, we shall consider the implications of this study for future research.

#### **What Kind of World?**

Our exploration of AIDS loss and the theology and spirituality that arise from this experience suggest the need for nothing short of a transformed world. Only this goal will allow us to meet the challenges posed by the AIDS pandemic. To respond adequately to

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<sup>1</sup> Bonnie J. Miller-McLemore and Herbert Anderson, "Gender and Pastoral Care," in *Pastoral Care and Social Conflict*, ed. Pamela D. Couture and Rodney J. Hunter (Nashville, Abingdon Press, 1995), 111. The reference to broken heartedness is drawn from Rita Nakashima Brock, *Journeys by Heart: A Christology of Erotic Power* (New York: Crossroad Publishing, 1988). The reference to the voice of God is from Charles Gerkin, "On the Art of Caring," *Journal of Pastoral Care* 45 (winter): 406.

the suffering inherent in AIDS and AIDS loss, a caring community must aim for the creation of:

- a loving world – The most important finding of the research is its demonstration of the power of love to heal the pain of loss. This finding suggests the value of creating a world in which those who live with AIDS and AIDS loss have the opportunity to experience transcendent love. While the experience of transcendence cannot be controlled, we can create conditions that foster love. Love may be experienced in beauty, in justice, in mutual relationships, in honesty and authenticity and in experiences that draw us beyond ourselves, such as prayer, worship and engagement with the arts.
- a just world. Governments, NGOs, corporations, churches and individuals must work to make resources for the prevention and treatment of AIDS accessible to all.
- a diverse world. The Trinitarian nature of God suggests that God delights in diversity. Human prejudice against difference in the form of racism, sexism and homophobia has hampered the response to AIDS and increased the extent of AIDS loss. In learning to treat all people equally and in celebrating the variety of ways in which humanity is embodied, the global community will experience benefits in the care of persons with AIDS and the prevention of HIV disease.
- an ever-renewing world. The promise of resurrection makes life with AIDS and AIDS loss tolerable. Hope may be found in witnessing signs of new life even amid pain and in learning to discern God's presence in life's most difficult experiences.
- a hospitable world. Experiencing diversity through welcoming and succoring those who differ is enriching. All Saints' experience testifies to the benefit of welcoming and supporting those who most need love, including the sick and the bereaved. Observing the ministry of this parish suggests that such service strengthens community at the same time as it expands the capacity to love.
- a unified world. AIDS has made it evident that all are interconnected. What happens in Africa affects life in San Francisco. Discoveries in Thailand and Mexico can help to alleviate suffering in the former Soviet Union. In short, AIDS has increased awareness of life in a global community. Further, global unity is strengthened when resources are shared for the benefit of all.
- a mindful world. No longer can people afford to live unconsciously. Life with AIDS has demonstrated that the consequence of choices made in the most intimate areas of life can echo around the world. As people learn to act more deliberately and consciously, personal and public health improve.

- a courageous world. Life with AIDS has demonstrated the folly of ignoring aspects of life that create discomfort. "Silence equals death," as ACT-UP has observed. Life with AIDS has also taught the value of honestly facing pain, suffering and limitation. When borne in a loving community, these difficult feelings may be transformed through shared strength and give rise to hope.
- a generous world. Controlling the spread of AIDS will require the richer nations of the world to share their resources with the developing nations. Countries do not live in a vacuum. Denying the poor access to resources for prevention and treatment will increase the death toll and further destabilize the global community. Generosity, in contrast, fosters peace as well as good health.

### **What Kind of Praxis?**

Achieving a transformed world in the age of AIDS requires two kinds of action.

First, the political structures and social attitudes that impede prevention, undermine human rights and hamper the provision of treatment require revision. Second, improved pastoral care of communities and individuals will enable more effective promotion of justice, increased hospitality to those in need, and heightened generosity and love. We shall now consider suggestions for action in each of these domains.

### **Toward an Ethic of Social Solidarity**

The purpose of this section is to address proposals for political and social change required by the global reality of AIDS. As this dissertation has indicated, AIDS has taken an enormous toll throughout the world. Besides the loss of millions of lives, many survivors continue to struggle with the emotional, spiritual and psychological effects of traumatic AIDS loss. This review has highlighted the importance of attending to the many contextual variables that influence susceptibility to HIV infection and the likelihood that a given individual will be adversely affected by AIDS loss.

With the advent of retroviral medications and their effectiveness in treatment in the Northern Hemisphere, there is an increasing tendency among wealthier nations of the world, and their church members, to view AIDS as a problem that has been solved. To adopt this stance is to deny the great need for prevention and treatment that still exists, particularly in Africa and Southeast Asia. Unfortunately, the cost of sophisticated treatment lies well beyond the means of most developing nations. While drug companies are beginning to make some concessions to bring their products within the reach of the poorer nations of the world, it is incumbent upon inhabitants of the wealthier nations to remain aware of local and global trends in infection and treatment. Without sufficient political will, it will be increasingly easy for the richer countries in the North to deny the needs of neighbors to the South, as well as to the needs of the many uninsured poor. In light of these trends, advocacy for resources for prevention and treatment is crucial. Compassion and solidarity are required in overcoming the temptations to denial and stigmatization. As long as anyone has AIDS, all of us have AIDS. As we have seen, failing to acknowledge human interconnection diminishes the effectiveness of prevention efforts and undermines the availability of resources for treatment.

As the study of All Saints suggests, there is an integral connection between love, memory and justice. The AIDS Quilt testifies to the power of these connections. The challenge facing individuals and institutions at all levels is to learn to draw on the dangerous power of remembrance to fuel efforts for change. Exercising vigilance is particularly important, since Lifton's work illustrates the dampening effect that psychic numbing can create in situations of traumatic loss. In light of this research, it is crucially



important for individuals and organizations to find ways to keep alive memories of love and loss and to draw on them in the service of change.

In his review of the plight of developing countries, Brian Boyle suggests several means of response. First, physicians can collect unused medications and make them available to those in need. Second, government, NGOs and corporations can aim towards greater cooperation in facilitating healthy care for and treatment of HIV-infected persons in the developing world. Third, pharmaceutical companies must be asked to provide increased assistance to developing nations in the form of cost reductions. Fourth, multinational corporations can build the infrastructures supporting increased profits by protecting their employees from increased infection. These goals can be achieved through providing resources for education and prevention to employees in situations of great risk. Fifth, the entire global community will benefit from ensuring that education and prevention efforts in developing countries are adequately funded and researched. Sixth, efforts at vaccine development provide a continuing hope for the eradication of HIV and, thus, deserve financial support.. Finally, addressing important social issues such as overcoming the shame and stigma associated with HIV, empowering women in countries where they have traditionally been subservient to men, and continuing research on breast-feeding will ease pressures on those most at risk of infection.<sup>2</sup>

As this review has demonstrated, protecting the rights of those who are ill and at greatest risk of infection will promote public health. Recognizing the many social and

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<sup>2</sup> Brian A. Boyle, "HIV in Developing Countries: A Tragedy Only Starting to Unfold," *The AIDS Reader*, 10, no. 2 (2000). [journal on-line]; accessed 15 August 2000; available from <http://www.medscape.com/SCP/TAR/2000?v10.n02/a7487.boyl/a7487.boyl-01.html>.

political factors that place individuals at increased risk of infection allows the global community to forge increasingly effective and compassionate responses to those most in need of aid. Courageously confronting social and political obstacles to prevention and treatment of AIDS offers promise for reducing the spread of HIV and lessening human suffering around the globe. In responding to the continuing spread of HIV disease, the insights of vulnerability analysis offer great promise in assisting efforts to learn from past failures and in fashioning effective interventions that honor the human dignity of those at greatest risk.

### Toward an Emancipatory Pastoral Praxis

In this section, the need for contextually sensitive and politically aware pastoral care will be considered. Our review of the social, political, psychological, theological and spiritual aspects of life with AIDS and AIDS loss has highlighted the multiple influences that shape this experience. This review suggests that pastors, like politicians and health workers, will provide more effective care as they educate themselves regarding the contextual factors that shape suffering with AIDS and AIDS loss. These contextual factors will greatly influence the manifestation of AIDS in their communities.

Perhaps the most debilitating factor in both the church and society's response to AIDS was denial. It was this factor, more than any other, that led to the widespread proliferation of AIDS throughout the world. It is essential, therefore, that pastors and churches learn to acknowledge honestly the presence of AIDS and AIDS loss in their communities. While these losses are more concentrated in some areas than others, virtually everyone has now had some first-hand exposure to AIDS or AIDS loss. Epidemiological research suggests that it is also particularly important for pastors to be

aware of the changing configuration of infection in their communities. For example, while the greatest number of deaths at All Saints have occurred among gay white men, African American members represent a population increasingly susceptible to the loss of family members and friends who may or may not be gay. Pastoral response, therefore, will benefit from increased sensitivity to the variety of communities increasingly affected by AIDS and AIDS loss.

Second, stigmatization has constituted one of the greatest sources of suffering in the AIDS epidemic. Therefore, actively affirming the dignity and worth of all people, including those living with AIDS and AIDS loss, is of great value. Stigmatization depends upon judgments about difference. Adopting pastoral strategies and theologies that affirm difference may decrease the tendency toward stigmatization.

Third, pastors and communities will benefit from the adoption of a systemic understanding of AIDS and AIDS loss. Pastoral care will improve with increased awareness of the sources of vulnerability predisposing individuals in a given context to AIDS and AIDS loss. Particular sources of vulnerability may include lack of education among youth, sexism and a resulting double standard for sexuality, drug abuse, the potential for sexual violence, and homophobia. As communities learn to analyze the social, political, psychological and theological factors that increase risk, they will become more effective advocates for the rights of those lacking the voice and resources to meet their own needs.

Fourth, pastors and communities can increase their sensitivity to the ways in which societal institutions, including the church, contribute to the oppression of the young, women, the poor, people of color, and gays and lesbians. Religious communities

must ask themselves, for example, how they increase suffering through their theological constructions and through the social norms that govern their lives. This study has demonstrated that traditional theologies of sin and sexuality have impeded the church's response to those living with AIDS. Further, the church's treatment of gays and lesbians has generally undermined pastoral efforts within the gay community. These factors severely hampered the church and society in responding to the AIDS pandemic in its earliest days..

Fifth, a wide variety of religious voices are responding to the AIDS epidemic. The religious community will benefit from understanding the contextual factors that influence these varied responses, engaging in dialogue amid difference, and finding ways to cooperate in life-giving pastoral work. Further, theologically sophisticated analyses of sexuality, health, and oppression have much to offer to the public discourse on AIDS.

Sixth, there is great need for education focused on the root causes leading to the proliferation of AIDS locally and globally. These causes include poverty, homelessness, sexism, illiteracy, militarization, immigration, fear of difference, and hypocrisy and denial about sexuality. Improving knowledge of the factors that promote AIDS will strengthen work for justice and promote increasingly effective pastoral care.

#### Concrete Proposals for Pastoral Praxis in Situations of Multiple Loss

In this section, we shall consider how pastors may respond to the pastoral needs arising in situations of multiple loss. Lifton's work suggests that pastors have a crucial role to play in recovery from traumatic loss. As we have seen, addressing questions of meaning and creating symbols lie at the heart of recovery from multiple loss. The

pastoral tradition has much to offer in each of these areas. Research on the plague and on AIDS

loss at All Saints has helped to illumine a number of specific pastoral strategies that may be helpful.

First, educating religious communities about the dynamics of grief and its healthy resolution will support more effective efforts to promote recovery from the bereavement associated with multiple loss. This education should attend to individual differences in the grief process, the particular challenges posed by multiple loss and cumulative loss, the varied beliefs and schemas that are altered by traumatic loss and their implications for theology and spirituality, the variety of strategies that help to resolve grief and the importance of achieving closure with the dying. Psychological research has helped to dispel a number of myths surrounding the grief process and exposure to these findings may improve the care pastors and communities provide to those who mourn.<sup>3</sup> Further, helping mourners and potential mourners to identify their bereavement burdens and impediments to coping may help them to marshal additional support in their efforts to heal from loss.

Second, research at All Saints suggests the value of affirming the presence of God amid pain and loss. Pastors can help mourners learn to lament: to honestly express to God all of the pain and anguish they are experiencing in the grief process. As we have

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<sup>3</sup> Psychologists Camille B. Wortman and Roxane Cohen Silver identify a number of these myths. They include the beliefs that disaster or depression are inevitable following loss, that distress is necessary and that failure to experience distress is indicative of pathology, the expectation that recovery will occur within a given time period and that grief will necessarily resolve over time. See their article, "The Myths of Coping with Loss," *Journal of Consulting and Clinical Psychology* 57, no. 3 (1989): 349-57, for more information about these myths.

seen, parishioners experiencing multiple loss may be overcome by anger and depression. Helping parishioners to become aware of these difficult feelings and helping to normalize them may allow them to work through these feelings rather than to become immobilized by them. Pastors must also be sensitive to issues of survivor guilt. Pennebaker's research, described in the previous chapter, suggests that providing parishioners and other mourners with opportunities to write and talk about the suffering they have experienced may help to alleviate this guilt. Helping parishioners to express their fear of losing their faith may also assist them in moving beyond crippling doubt and in forging increasingly effective theological worldviews that are robust enough to sustain them in situations of traumatic loss.

My work at All Saints has taught me how important sacramental, musical and liturgical resources can be in alleviating grief. These resources allow for the expression of emotion in a multi-sensory context. They also provide a rich symbolic context, thus addressing the need Lifton has found in survivors for the revival of the capacity to create symbols. Pastors can draw on rich liturgical and artistic resources in ministries of healing and care of the dying and bereaved.

Both Julian's experience and the experience of All Saints demonstrate the healing power of prayer. Prayer provides an arena in which God's love may be experienced. The experience of All Saints parishioners has demonstrated how the communal practice of intercessory prayer provides a way of sharing the emotional burdens of caregivers and mourners. This research suggests that interceding to patron saints may be of particular value when mourners are experiencing a sense of anger or distance from the Divine.

Affirming the strength of caregivers and survivors is also important. Normalizing troubling aspects of traumatic loss, including the death imprint, survivor guilt, psychic numbing and counterfeit nurturance are essential in alleviating distress. Helping survivors to see themselves as strong and as capable of healing from loss may provide them with hope.

Pastors may also benefit, in particular, from recognizing the ways in which care for the dying, particularly those dying from such a debilitating disease as AIDS, may create opportunities for them to incarnate powerfully God's love in new ways. This research revealed that pastors face ethical and moral quandaries in their ministry to the dying. The pastoral caregiving community can help pastors to share their experiences of ministering to the dying honestly and educate them to respond authentically and faithfully to the perplexing questions that arise at life's end. Such education and honest sharing may help to reduce the anxiety pastors experience in ministry amid traumatic loss, and it may also decrease the susceptibility to burnout.

Research at All Saints has demonstrated how helpful it is for a grieving community to have opportunities to gather together in times of loss. Parishioners at All Saints commented on the usefulness of "wakes" in the rectory and the shaping of a "second" requiem on Sunday for the parish family when important parishioners die. Further, the annual service of AIDS remembrance provides a chance for parishioners to come together around their loss, as do anniversary celebrations on the day of death for important parishioners. All of these strategies facilitate the honest sharing of feelings, including sadness and grief, and they help further to decrease the isolation that can hamper the mourning process.

Perhaps the most useful resource is remembrance. At All Saints, the community profited from the construction of a special space dedicated to the memory of the departed. The addition of the columbarium will provide another resource for remembrance. Further, the annual service of remembrance consecrates a special time to remember loved ones. On several occasions, parishioners gathered to create a square for the AIDS quilt on behalf of departed members, and this activity provided them with a way to share memories and, thus, to support one another through loss. Finally, Kenneth Schmidt's gift for telling warm personal stories about the departed proved to be an important pastoral resource for the entire community. The sharing of stories facilitated remembrance, but more importantly, it allowed celebration of the uniqueness of each and every deceased parishioner.

The people of All Saints have taught me how "dangerous memories" of the departed can undergird efforts at advocacy. Healing is facilitated through serving those in need and addressing openly the injustices that contributed to the suffering of AIDS and AIDS loss. These efforts take on particular meaning when they are done in the name of the beloved dead.

Finally, the experience of All Saints has emphasized the importance of facing loss authentically. All Saints has a clear identity, and members of the parish have lived it out despite the fact that it has not always been consistent with the "Anglican" or "Episcopal" status quo. In my experience, congregations are sometimes able to lead the denomination in responding to particular issues because of important experiences they have shared. I believe that All Saints led the way in the seventies and eighties in its ministry to and with gays and lesbians. I appreciate the congregation's courage in living out this aspect of its



identity and appreciate the fact that its authentic approach to sexuality was an important factor in the success of All Saints' ministry to those living with AIDS and AIDS loss. The authenticity of parishioners regarding this issue became a gift of grace to many who were able to find in this community and its members the support and love they needed in a time of tremendous loss.

### **Implications for Future Research**

Implications for future research regarding a pastoral response to multiple AIDS loss grow directly from the limitations of the present research. First, the conclusions I have reached are based on the study of just one congregation. Therefore, it would be useful to study other congregations and religious communities to determine how these findings may be nuanced for ministry in other settings. Further, I have relied on qualitative research methods. Thus, it is impossible to generalize from these results to a wider population of churches. This is all the more reason to study the response of other congregations to AIDS loss.

With regard to the historical portion of this analysis, I have relied primarily upon a single primary source, the writings of Julian of Norwich, in the comparative analysis. It would be useful, therefore, to examine other pastoral responses to the Black Death to determine first, whether they support the conclusions that have arisen in this research and second, whether they offer additional insights.

It would also be useful to explore further parallels between the experience of multiple AIDS loss and other types of multiple loss. Lifton's analyses proved helpful in a number of situations of traumatic loss and this finding suggests that the results and recommendations of the present study may also offer promise in other settings of multiple

loss. The exact applicability of these results, however, must await future research. Based on the present findings, I would expect that creating a climate of love, authenticity and acceptance, fostering a communal response, and creating robust symbols would be critical factors in shaping a pastoral response to other forms of multiple loss.

Finally, I have been encouraged by the fruits of the practical critical correlational method developed for this study. The comparison of theological and spiritual responses to the Black Death and AIDS yielded some intriguing parallels in pastoral praxis. In addition, application of the method helpfully illuminated important similarities in the human experience of multiple loss in two very different times and contexts. The central finding -- that a transcendent experience of God's love provides a potent source of healing from multiple loss -- gained force through its manifestation in two very different historical settings.

The method will benefit from its application to other critical issues in pastoral care, such as the development of a pastoral theology of sexuality, an exploration of the usefulness of lament in situations of loss, and a consideration of the process of symbol formation as an aid to healing from loss. In particular, its further use may clarify important aspects of cultural contexts that affect critical conversations across time. It seems particularly suited to highlighting parallel and contrasting features of complex human predicaments in different historical situations. The method can, however, profit from clearer criteria for analyzing the religious aspects of the human experiences to which it is applied. Tracy's work on critical correlational will be a helpful resource.

## **Conclusion**

With the provision of these concrete proposal for transformed praxis, this study of the effects of AIDS loss has come full circle. The critical insights arising from my initial pastoral experience with AIDS and AIDS loss have been honed through thick description of the phenomenon of AIDS loss, historical analysis, ethnography and critical correlation. These analyses have confirmed certain pre-judgements that gave rise to my passion for this research, including the beliefs that the power of love is greater than the power of death and that human cooperation with the Divine in the creative response to suffering facilitates healing and renewal. It has also yielded surprising new insights, including awareness of the powerful connection between a transcendent experience of love and healing. I have discovered key links between self acceptance and self-transcendence in developing a healthy spirituality in the face of loss and have observed first-hand the power of memory and symbol creation in responding to the devastation of AIDS. Finally, the critical correlational practical method developed for this research has increased my awareness of the need for pastors to mobilize public action, in addition to pastoral concern, in responding to AIDS loss. It now remains to consider more specifically how this analysis has wrought personal, as well as professional, transformation.

## CHAPTER 12

### A PERSONAL REFLECTION ON THE RESEARCH AND ITS FINDINGS

My attempt to understand and fathom the implications of my life and work with AIDS and HIV has been a long and arduous journey. My pastoral exposure to AIDS shook my world far more than the Loma Prieta quake I experienced at the outset of this ministry. Eleven years later, I know that I will continue to reflect on the central finding of this research for the rest of my life. How, exactly, does love exert its healing effects on the souls of those who mourn? Perhaps these words of Fenton Johnson, writing of the effects of his lover's death, may help to elucidate the profound relationship between grief and love that has arisen in this work. Fenton writes:

Grief is love's alter ego, after all, yin to its yang, the necessary other; like night, grief has its own dark beauty. How may we know light without knowledge of dark? How may we know love without sorrow? 'The disorientation following . . . loss can be terrible . . . but grief gives the full measure of love, and it is somehow reassuring to learn, even by suffering, how large and powerful love is.'\*

My confrontation with multiple AIDS loss in San Francisco, and more particularly, at All Saints has surely demonstrated to me the large and powerful measure of love. My life has been immeasurably enriched through this knowledge, and I give thanks for the lives and legacies of those whose love has increased my own appreciation of love's force.

In exploring the effects of this research, I shall address four issues: my own dynamics as a survivor, my commitment to justice, the power of community and my

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\* Fenton Johnson, *Geography of the Heart*, 233. The quotation is from a letter of Wendell Berry to Johnson.

understanding of this work as the continuation and completion of my ministry with AIDS.

I became aware in the course of my research that, like Julian and the people of All Saints, I also was a survivor of multiple loss. I understand my own losses to be both related and unrelated to AIDS. My life history was profoundly shaped by the deaths of my grandfather at age 3 and my younger sister at age 5. Because of these early experiences with death, I have tended to feel a certain comfort with death. However, this comfort was hard won; I achieved it through a course of therapeutic work following the death of my closest friend to cancer when I was 33. My growing comfort with death in my 30s led me to chaplaincy; and my passion for justice led me to AIDS ministry. What sustained me in the work, despite its difficulties, was the presence of God that I experienced as love: the love of the gay community, the love of the caregivers on Ward 5A, the love of my fellow chaplains and that sense of intensity and community described by my interviewees that I also experienced. I found life in the midst of AIDS to be fuller: pain *was* more painful, but joy and love were more intense in the atmosphere of imminent death that surrounded life with AIDS in San Francisco in the early 1990s. Although I wrestled with difficult questions and concerns in this work, never had I felt more alive.

Living with intense emotion and imminent death, however, does take its toll. I left San Francisco in the summer of 1992 with regret *and* relief. Nevertheless, my life had been profoundly changed through my AIDS ministry, and I continued to ponder the questions it had raised. The experience of reading Julian of Norwich combined with my return to San Francisco awakened in me the desire to continue my AIDS work. Yet, even with the desire, I faced uncertainty. Would I have the strength to re-enter the trenches?

My uncertainty led me to a Jesuit priest who helped me to do an "Ignatian" style discernment of my choice of dissertation topic. In considering AIDS as a topic, I was aware of an anticipatory grief reaction, and it was so intense that I feared that I might not be able to sustain myself in the course of the research and writing. With the help of Father Tom Powers, I explored this reaction, as well as my sense of call toward this topic. After a two week period of reflection, I decided that this was the work I wanted to do, and I began writing my proposal with a sense of peace.

Later, I was very happy that I had taken the time to do this preliminary soul searching. I found this research to be demanding and exhausting at times. I was most affected by two things: first reading the writing of Robert Lifton, Kai Erikson and David Nord, and second interviewing All Saints parishioners. Reading the psychological work on traumatic loss was difficult and distressing. I found, however, that it very helpfully illuminated the primary texts from the Black Death. Further, it illuminated my own early experiences with death and their subsequent effects on my life. Reading these works made it impossible for me to avoid the reality of death, just as I had found it impossible in my AIDS work. My mid-life confrontation with death, however, had a bittersweet poignancy that had not marked my earlier encounter with AIDS. In confronting Lifton's work, in particular, I understood that in my engaging this research focus, I was experiencing all of the psychological characteristics of survivors that he described. While I found this challenging, I understood that I *also* had a survivor mission, exemplified in this dissertation. I wanted to redress the wrongs that people living with AIDS experienced.

In the course of this work, therefore, I re-discovered a passion for justice. The

intensity of it caught me by surprise. At the same time, it energized me and transformed me. One fruit of this research is courage. I have achieved greater clarity about aspects of my theology, and I hope to continue to address the issues of sexism and heterosexism that have handicapped my own church's ability to express God's unconditional love. I encountered my passion for justice in an intense way in my AIDS ministry. Encountering it again in the research and writing motivated me, empowered me and fulfilled me, as I found a new way to express this passion through the creative work of authorship.

Another surprising and delightful aspect of this research was the power of community. I was excited at the willingness of All Saints parish to welcome me into their midst as a researcher, and I was moved by the extent of emotion that parishioners shared with me in the interviews. In completing his work with Hiroshima survivors, Lifton described the vividness of emotion in the survivors he interviewed, despite the fact that the events he was exploring with them had occurred nearly twenty years before. I, also, was surprised at the clarity of memory and intensity of emotion that surrounded the early experiences of AIDS at All Saints. I am deeply grateful to the parishioners who were willing to re-visit these difficult days with me. I appreciated, also, the friendship of Kenneth Schmidt and his honesty in sharing his pastoral experiences with me. He truly became a companion in the course of this project. Finally, I am indebted to Lloyd Prator and Judith Dunlop for their willingness to share intimate details of their lives and ministries with me.

In this research, I re-visited the ravages of AIDS. My respect for its destructive power was renewed. Further, I knew once again a fear of the disease that I had experienced previously. AIDS represents death, perhaps not as vividly in the Bay Area in

2000 as in 1990; however, it still has the power to inspire fear. This fear is both rational and irrational. While working on this project, I experienced depression, sleep difficulties and rumination. They were undoubtedly due to my fears of contagion and death. To deny these fears would be dishonest, yet to succumb to them is unthinkable. My work with AIDS gave birth to compassion, and I hope that my compassion for those living with HIV disease will never die.

As I conclude this research, I have many unanswered questions. How can my experience, the experience of All Saints and of the Episcopal Church in San Francisco be a resource for the millions around the world still living with HIV disease? What does the future hold for those who continue to suffer from the pain of AIDS and AIDS loss? I am deeply moved by the plight of those in Africa South of the Sahara, in particular, as AIDS continues to rage through their families, their communities and their nations. They do not have the luxury of time to reflect unaffected by frequent loss – as I consider their plight, I pray that God will continue to work through the efforts of scientists, doctors and caregivers to alleviate the suffering they experience.

In my interviews with Kenneth Schmidt and Lloyd Prator, each pastor described a moment when, through God's grace, he experienced a sense of fulfillment in knowing that he had been faithful to God's call to respond to the pain of AIDS. In different ways, each received affirmation of his strength and reassurance that he had completed the ministry to which he had been called.

In completing this dissertation, I have experienced a similar sense of completion. Perhaps, like Julian, I shall continue to reflect for twenty years on the learnings I have discovered. More likely, I shall have opportunities to apply them in new ways.



Regardless of what lies ahead, I have been deeply privileged by the companionship I have experienced, and I pray that I shall continue to be a faithful witness to the awareness of God's love, experienced amid AIDS, with which I have been entrusted.

## APPENDIX I

### GROUNDING THEORY ANALYSIS

The purpose of this appendix is to provide a general introduction to the development of grounded theory. Grounded theory analysis is not well known within the field of pastoral care and counseling, yet, as this dissertation has illustrated, the method may be fruitfully applied to the development of inductive theory within the theological and pastoral disciplines. For that reason, I have provided this brief introduction to the method, so that researchers interested in its application may become better informed about the rationale governing its use in the present work.

#### **Introduction to Grounded Theory**

Grounded theory is not, strictly speaking, a method of data collection. Instead, it is a form of qualitative data analysis. According to Strauss and Corbin, the grounded theory approach is “a qualitative research *method* that uses a *systematic* set of procedures to *develop* an inductively derived grounded *theory* about a *phenomenon*.”<sup>1</sup> The result of grounded theory research, therefore, is a theoretical formulation about a particular phenomenon of interest that is drawn from empirical data. Two sociologists, Barney Glaser and Anselm Strauss, developed the grounded theory method in the 1960s. Each of them hailed from academic institutions with a strong history of qualitative analysis – Strauss from the University of Chicago and Glaser from Columbia. Both were interested in the relationship between empirical research in the field and the development of theory. Strauss, in particular, was interested in the effects of change and process in experience, while Glaser was interested in formulating systematic procedures for coding and testing hypotheses that arose in research.<sup>2</sup>

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<sup>1</sup> Strauss and Corbin, *Basics of Qualitative Research*, 25 (original emphasis).

<sup>2</sup> Ibid.

The originators of grounded theory sought a method of theoretical analysis that would close the gap between theory and research. They were interested in developing theory that would provide insight into a specific area of study. To achieve this goal, they developed methods that reverse customary approaches. Rather than building theory primarily in a deductive fashion, grounded theorists work inductively from data.

The research strategy developed by Glaser and Strauss has a number of distinctive features. First, their method involves “comparative analysis”: it relies on systematic processes of comparison and questioning. Second, in grounded theory research, the collection, coding, and analysis of data occur simultaneously.

According to Glaser and Strauss, grounded theory may be of two types. *Substantive* theory is theory developed for a substantive or empirical area of research such as patient care, race relations, or delinquency. *Formal* theory is theory developed for a formal or conceptual area of inquiry. Examples include stigma, deviant behavior, authority and power, or social mobility.<sup>3</sup> Both types of theory are described by the authors as “middle range” – that is, they fall midway between working hypotheses and so-called “grand” theory. However, substantive theory is more specific than formal theory, since it is based in a particular area of inquiry. For example, Glaser and Strauss developed a grounded theory focused on the awareness of dying in medical settings and its implications for patient care. They note that it would be possible to combine this research with other research focused on awareness, such as spying, to develop a formal theory of awareness. The authors describe how formal theory may be developed from

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<sup>3</sup> Glaser and Strauss, *Discovery of Grounded Theory*, 32.

substantive theory. While varying strategies characterize the formulation of these two types of theory, the authors emphasize their central similarity: both are grounded in data.

Strauss and Corbin describe four characteristics that may be used to judge the applicability of a grounded theory to the phenomenon that shaped it.<sup>4</sup> First, the theory must *fit* the everyday reality of the area under investigation. The degree of fit generally improves when grounded theory is based on increasingly diverse data. Second, the theory should be *comprehensible*. It should make sense both to theorists and practitioners who are familiar with the type of data giving rise to the theory. Third, the theory should have a degree of *generality*. It should be abstract enough and encompass enough variation in the phenomenon to be useful in a variety of contexts. Fourth, the theory should provide *control*. That is, it should provide guidelines for action related to the phenomenon studied. Good grounded theory generates hypotheses about the conditions affecting the phenomenon in question and its consequences. This analysis, therefore, should lead to some ability to guide action and make predictions about the phenomenon in question.

Grounded theory consists of several elements. The first element of a grounded theory are conceptual categories and their properties. Both the categories and their properties emerge from the data, but they are not the data themselves. Instead, categories and the properties pertaining to them are formed through comparisons made and questions put to the data. They result from a process of conceptualization.

A second element of grounded theories are hypotheses or generalized relations among these categories and their properties. Strauss and Corbin speak of these

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<sup>4</sup>Strauss and Corbin, *Basics of Qualitative Research*, 23.

relationships in terms of a paradigm model.<sup>5</sup> The model attempts to specify the causal conditions that give rise to a phenomenon. It also addresses the context in which it is observed, intervening conditions that may affect its manifestation, actions and interactions related to it, and its consequences.

A third element in grounded theories is the process of theory integration. Theory integration results from the identification of the core category, “the central phenomenon around which all other categories are integrated.”<sup>6</sup> Theory integration occurs as the researcher specifies the relationships between the core category and subsidiary categories by means of the paradigm model. Other aspects of theory integration include examining relationships between categories as a function of their dimensions, namely, the continua along which they may vary. For example, in a study of high risk pregnancy, researchers were interested in the effects of cues about the nature of risk factors as pregnant women perceived them. They explored the relationships between the various dimensions of the cues and the degree of crisis associated with the pregnancy. After examining these relationships, researchers attempt to verify them with data. The final aspect of theory integration consists of filling in categories that may need further development.

Developers of the grounded theory method specify a number of researcher characteristics associated with successful application of the method. These characteristics include, first, creativity. In their view, creativity derives from the ability “to break through *assumptions* and to create new order out of the old.”<sup>7</sup> The various guidelines

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<sup>5</sup> Ibid., see especially chap. 7.

<sup>6</sup> Ibid., 116.

<sup>7</sup> Ibid., 27.

Glaser, Strauss, and their associates offer for working with data are all designed to foster the ability to think creatively.

A second, important researcher characteristic in grounded theory work is theoretical sensitivity. Strauss and Corbin define this as “the attribute of having insight, the ability to give meaning to the data, the capacity to understand, and capability to separate the pertinent from that which isn’t.”<sup>8</sup> This sensitivity refers to work at the conceptual level. Sources of theoretical sensitivity include familiarity with the literature, professional and personal experience, and the analytical process that is designed to foster it. Besides specifying factors influencing the development of theoretical sensitivity, Glaser, Strauss and their associates provide suggestions for increasing it. They advocate the importance of maintaining an attitude of skepticism, following grounded theory procedures, and repeatedly questioning the data.

### **The Process of Developing Grounded Theory**

As noted above, the developers of grounded theory research have outlined a systematic process for data analysis. Grounded theory research begins with the identification of a clear research problem. The method works best when the chosen research question provides researchers with the flexibility and freedom to explore a phenomenon in depth.<sup>9</sup> According to Strauss and Corbin,

*The research question in a grounded theory study is a statement that identifies the phenomenon to be studied. It tells you what you specifically want to focus on and what you want to know about this subject. Grounded theory*

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<sup>8</sup> Ibid., 42.

<sup>9</sup> Ibid., 37.

questions also tend to be oriented toward *action and process*.<sup>10</sup>

The research question in grounded theory work may be focused on interactions, organizational issues or biographical concerns. Strauss and Corbin specify a number of sources of research questions, including previous research, the technical literature in a given area, or personal or professional experience.<sup>11</sup>

The developers of grounded theory research devote a great deal of attention to the use of literature in grounded theory work. Literature may be used either as a source of data or as a way of locating gaps in a particular area of research. The identification of gaps can open the way to grounded theory work focused in this area. Strauss and Corbin emphasize that it is not essential in grounded theory research for investigators to exhaustively review the literature pertaining to the phenomenon of interest before collecting data. This is because theoretical constructs in grounded theory work emerge from the data rather than from previously existing research. The literature can be helpful, however, in suggesting theoretical concepts, in identifying variables for study, and in exploring the relationships between them. Reviewing existing research can also heighten theoretical sensitivity, because it can provide interesting questions about one's own data.

Once researchers have identified the research question, they must then decide what groups to include in their preliminary data gathering. The initial decisions for the theoretical collection of data are based on "concepts derived from literature or experience."<sup>12</sup> They may also be affected by such factors as "access, available resources,

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<sup>10</sup> Ibid., 38 (original emphasis).

<sup>11</sup> Ibid., 34-36.

<sup>12</sup> Ibid., 180.

research goals and...time and energy.”<sup>13</sup> Researchers begin with a few “local” concepts regarding the structures and processes in the areas of study. For example, in hospital work, they know there will be “doctors, nurses and aides, and ward and admission procedures.”<sup>14</sup> These give the researchers a starting place, but they do not know how these aspects of the situation will affect the data and emerging theory. Their theory is more likely to be focused on the problem of interest, not the situation in which it arises. Further, standard “local” concepts may become irrelevant to the work, and the researchers may discover “many more structural and professional ‘local’ concepts than [they] could have anticipated before [their] research.”<sup>15</sup> The evolving theory may also lead to modification of earlier decisions about data collection.

Besides deciding on the initial groups and sites, researchers must also decide upon the method of data collection and the kinds of data to use. The data in grounded theory research can be obtained through a number of methods, including interviews, field research, reviews of documents or audio and videotapes, and surveys. It can also be derived from earlier research projects in a given area of interest.

Once these initial decisions have been made, theoretical sampling begins. Theoretical sampling refers to “the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes [the] data and decides what data to collect next and where to find them, in order to develop [the] theory as it emerges.”<sup>16</sup>

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<sup>13</sup> Ibid., 179.

<sup>14</sup> Ibid., 45

<sup>15</sup> Ibid., 46.

<sup>16</sup> Glaser and Strauss, *Discovery of Grounded Theory*, 45.



Theoretical sampling, therefore, involves ongoing sampling of groups. This process rests upon continuous thought, analysis, and research. The choice of groups depends upon their theoretical relevance for furthering the development of emerging categories. Group selections are also made to increase the scope of the theory and to increase its conceptual level. Usually, comparison groups are chosen in accordance with the emerging theoretical framework. These groups may be chosen either to maximize or minimize similarity with existing groups. As Glaser and Strauss note, "*This control over similarities and differences* is vital for discovering categories, and for developing and relating their theoretical properties, all necessary for the further development of an emerging theory."<sup>17</sup> Minimizing differences increases the possibility of collecting data on a given category and noting differences within it. It also helps in specifying the conditions under which given categories emerge. Maximizing differences leads to the collection of different and varied data bearing on particular categories. It uncovers strategic differences among groups that increase a theory's scope.

An important issue in grounded theory research is deciding upon the number of groups one should study. Consideration of this issue introduces another important concept in grounded theory research, namely, theoretical saturation. The general rule of thumb in grounded theory research is that one should sample until theoretical saturation is achieved. Theoretical saturation means that "no additional data are found whereby the sociologist can develop properties of the category."<sup>18</sup> A judgment that saturation exists occurs when the researcher sees similar instances of the category in question over and

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<sup>17</sup> Ibid., 55 (original emphasis).

<sup>18</sup> Ibid., 61.

over. In trying to reach saturation, researchers must maximize group differences in order to maximize the variety of data bearing on a given category. The criteria for determining saturation are “a combination of the empirical limits of the data, the integration and density of the theory, and the analyst’s theoretical sensitivity.”<sup>19</sup>

The development of grounded theory from data requires three methods of data analysis. These procedures are at the heart of the grounded theory approach. The first method, *open coding*, describes “the process of breaking down, examining, comparing, conceptualizing, and categorizing data.”<sup>20</sup> This process proceeds through asking questions and making comparisons for similarities and differences between appearances of phenomena. In open coding, categories emerging in the data are given conceptual names. Further, these categories are developed first in terms of their properties, and second, their dimensions. The latter are the continua along which they may vary.

The second form of analysis in grounded theory research is axial coding. Axial coding uses the paradigm model described above to explore relationships between categories and subcategories. The focus in axial coding is on specifying the *conditions* that give rise to a category; the *context* in which it is embedded; the *action/interactional strategies* by which it is handled, managed or carried out; and the *consequences* of these strategies. Researchers also continue to attend to any new properties and dimensions of categories they observe. Once again, key processes in axial coding include asking questions and making comparisons.

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<sup>19</sup> Ibid., 62.

<sup>20</sup> Strauss and Corbin, 61 (original emphasis).

The final method of analysis used in grounded theory research is selective coding. Selective coding is at the heart of theory integration. It involves, “the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development.”<sup>21</sup> This is clearly the most challenging and complex part of developing grounded theory. The aim in selective coding is to choose a core category. This may be understood as the central phenomenon around which all other categories are integrated.<sup>22</sup> The story line must explain the relationship between the core category and other categories observed. Further, it must elaborate the relationships between the core category and subsidiary categories in terms of the paradigm model. In addition, the relationships specified must be supported by data. Ongoing theoretical sampling at this stage is devoted to verifying these relationships and to filling in the categories.

Besides developing and specifying methods for data analysis, Strauss and his associates also attend to centrality of process in the study of phenomena. To this end, Strauss and Corbin describe two additional aspects of theory development. These include specifying processes observed in the phenomenon of interest and examining consequences and conditions related to the phenomenon through a conditional matrix. In attending to process, they focus on the action and interaction sequences related to the research phenomenon of interest. They conclude that, typically, researchers can describe process in two ways. First, process can be conceptualized as phases or stages of development, transformation, socialization and so on. Second, process can be understood

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<sup>21</sup> Ibid., 116.

<sup>22</sup> Ibid.

as a non-progressive movement. The handling of chronic illness provides an example of nonprogressive process.<sup>23</sup> As they note, chronic illness course can be broken down into phases, however, a person does not normally move between these phases in an orderly progressive fashion. It is important in introducing process within one's theory to attend to the conditions that give rise to the central phenomenon and to understand the corresponding changes in action and interaction that they bring.<sup>24</sup>

Finally, Strauss and Corbin describe the analysis of action and interaction sequences in terms of the conditional matrix.<sup>25</sup> The conditional matrix explores increasingly wider contexts that may impact action and interaction related to a phenomenon in question. The matrix is useful for opening up the wide range of conditions that affect a given phenomenon. For example, in their analysis of work flow in a hospital situation, Strauss demonstrated how a nurse's inability to supply a physician with the right size rubber gloves impeded the process of examination. As Strauss and Corbin noted, viewing this phenomenon through the conditional matrix provided a way of specifying the impact of the AIDS epidemic at a national level upon the work flow in this very particular hospital situation. It was possible to trace the impact of national events upon processes at the progressively simpler levels of analysis specified in the conditional matrix.

Advocates of grounded theory research spend some time exploring the differences between quantitative research and the qualitative approach that characterizes grounded

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<sup>23</sup>Ibid., 156.

<sup>24</sup>Ibid., 157

<sup>25</sup> Ibid., 158-75.

theory. The basic difference they highlight is a primacy of emphasis: quantitative research tends to emphasize theory verification. In contrast, the grounded theory method, a qualitative approach, emphasizes theory generation. Glaser and Strauss do note that “each form of data is useful both for the verification and generation of theory.”<sup>26</sup> Grounded theorists state, in addition, that it is possible to redefine the canons of “good science” “to fit the realities of qualitative research and the complexities of social phenomena” that grounded theorists seek to study.<sup>27</sup> These canons included such standards as significance, theory-observation compatibility, generalizability, consistency, precision, and verification. These re-definitions, in their view, need not be dominated either by models from the physical or biological sciences or from quantitative social research. To aid further the assessment of grounded theory work, Strauss and Corbin offer a number of evaluative criteria.

Finally, Glaser and Strauss specify the reasons why they choose to focus on qualitative data. They prefer it because:

- the crucial elements of sociological theory are often found best with it
- more often than not, qualitative research is the end product of research within a substantive area “beyond which few sociologists are motivated to move”, and
- it is most often the most “adequate” and “efficient” way to get the type of information required and “to contend with the difficulties of an empirical situation.”<sup>28</sup>

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<sup>26</sup> Glaser and Strauss, *Discovery of Grounded Theory*, 18 (original emphasis).

<sup>27</sup> Strauss and Corbin, *Basics of Qualitative Research*, 250 (original emphasis).

<sup>28</sup> Glaser and Strauss, *Discovery of Grounded Theory*, 18.

Clearly, the grounded theory method provides researchers from a variety of disciplines with carefully developed and well-specified tools for data analysis and theory generation. My impression is that while this method is not well known within my own discipline of pastoral care and counseling, it has great potential to contribute to theoretical advance within it.

## APPENDIX II

### ALL SAINTS PARISH: A STATISTICAL SUMMARY OF CERTAIN TRENDS PAROCHIAL REPORT ATTENDANCE AND FINANCIAL DATA

The purpose of this table is to summarize data describing key characteristics of All Saints Church, including attendance data and revenue data collected over a twenty-two year period. Data for this appendix were drawn from the annual parochial reports which the congregation submits to the National Church Office each year. This data provide a bird's eye view of gains and losses in membership as well as fluctuations in giving that may be attributed to changes in membership.

<u>Congregation</u>	1978	1979	1980	1981	1982*	1984	1985	1986	1987	1988	1989
# families	18	12	14	14	29	24	34	35	36	25	31
# individuals	80	43	57	58	70	90	101	102	108	98	117
#households	98	65	72	72	99	114	135	137	144	123	146
<u>Membership</u>	1978	1979	1980	1981	1982	1984	1985	1986	1987	1988	1989
total baptized	120	73	102	107	142	192	192	206	192	192	167
total losses							5	21	8	44	7
present number							129	185	184	148	160
<u># Confirmed</u>	1978	1979	1980	1981	1982	1984	1985	1986	1987	1988	1989
<u>Communicant</u>											
Good standing	121	130	82	104	105	126		146	138	138	119
Losses	0	72	2	3	5	4		21	8	37	7
Present # good standing	121	58	80	101	100	122		125	130	101	112
<u>Attendance</u>	1978	1979	1980	1981	1982	1984	1985	1986	1987	1988	1989
First Sun. Lent	46	35	60	64	95	103	96	98	76	72	53
Easter	151	95	171	151	223	217	214	179	120	127	159
Pentecost	34	35	63	83	78	85	69	80	78	65	72
First Sun. Adv.	47	31	67	72	71	88	92	113	86	72	103
<u># Pledges</u>	1978	1979	1980	1981	1982	1984	1985	1986	1987	1988	1989
	27	31	49	55	67	93	92	80	73	60	61
<u>Total Pledges**</u>	1978	1979	1980	1981	1982	1984	1985	1986	1987	1988	1989
	8	16	23	25.2	32.6	48.6	59.8	47.1	54.4	51.5	53.7

\* data for 1983 are missing

\*\*in thousands of dollars

## APPENDIX II

<u>Congregation</u>	1990
# families	21
# individuals	103
#households	124

<u>Membership</u>	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
total baptized	172	172	186	194	174	146	154	166	163	178
total losses	10	2	9	9	52+	4	5	8	1	2
present number	162	179	177	185	137	142	149	158	162	176

<u>Confirmed</u>	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
<u>Communicants</u>										
Present # good standing	118	123	130	143	134	117	128	133	144	160^
Losses	10	--	--	--	--	--	--	--	--	--
Others active	--	14	24	28	26	40	36	26	25	30

<u>Attendance</u>	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
First Sun. Lent	96	77	85	80	91	81	88	77	74	--
Easter	223	190	194	180	216	214	195	232	218	200
Pentecost	68	77	64	85	93	88	88	95	113	--
First Sun. Adv.	119	107	86	90	79	104	84	71	103	--
Average Sun.	--	--	86	91	85	85	88	93	106	89

<u># Pledges</u>	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
	78	67	76	90	83	92	93	91	93	93

<u>Total Pledges*</u>	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
	68.8	78	86.9	90.6	101.9	114	111.7	116.1	123.5	123.5

+Figure appears to represent adjustment of records

\*in thousands of dollars

^ No. of communicants



PAROCHIAL REPORT FINANCIAL INFORMATION  
1989-2000

<u>Revenue +</u>	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
Total general	84.3	105.4	115	117	121.5	127	140.5	148.2	143.1	147.5	150.2
Total special	117.6	187.2	40.2	52.7	102	93.2	88.1	41.5	28.9	46.1	35.4
Receipts *	115.3	88.7	--	--	--	--	--	--	--	--	--
Total	321.3	381.4	155.3	169.8	223.6	220.2	228.7	189.8	172.1	193.7	185.6

+ in thousands of dollars

\* Non-income receipts

<u>Expenditures+</u>	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
Work outside	21.9	23.1	13.2	29.6	30	29.4	20.8	24.2	25.8	25.2	41.8
Parish	224.8	289.8	118.6	151.2	107.3	128.4	215	153.6	143.1	153.3	162.6
Disbursements*	70.2	67.9	--	--	--	--	--	--	--	--	--
Total	321.3	380.9	131.8	180.9	137.3	157.8	235.8	177.9	160.0	178.6	204.4

+ in thousands of dollars

\* Non-expense disbursements

Trust/Endowt. *	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
	285.3	288.3	277.0	348.3	395.3	407.7	398.7	436.8	436.4	430.4

+ in thousands of dollars

### APPENDIX III

#### RESULTS OF THE DEMOGRAPHIC AND ATTITUDINAL SURVEY

This appendix includes the survey cover letter, a copy of the survey form with the results obtained from its administration to parishioners, and a summary sheet of other findings.

#### Cover Letter

3 April 2000

Dear Fellow All Saints Parishioner:

As many of you know, I am currently working on a dissertation focused on AIDS bereavement. As a part of this work, I am exploring the experience of AIDS loss at All Saints Church and the effect that this loss has had on the parish and its members.

I am writing to you to ask for your assistance in this research. As part of my research, I am compiling various sorts of data about the parish. I am particularly interested in being able to describe accurately the kinds of people who attend All Saints and their beliefs about their church and spiritual life.

I am writing to ask you to take a few minutes to fill out the enclosed survey. I have enclosed a stamped, self-addressed envelope so that you can return it to me directly when you have finished. I am not asking everyone in the parish to fill this out – I have chosen your name from the directory as part of a random sample. It is very important that I receive your response!! With each survey I receive, I am able to describe All Saints with greater accuracy, and, therefore, your participation is very important to this research.

Would you please fill out and return your survey to me by April 15<sup>th</sup>?

Please feel free to call me if you have any questions about this survey. Also, if there is any question that you would prefer not to answer, please feel free to leave it blank.

I want to add a word about confidentiality. I have marked the enclosed envelope with a number to identify you, so that I am able to track who has responded. When I receive your response, I will check your name off the list. Then I will throw out the envelope and keep the survey sheets separate from them. There is nothing on the survey sheet itself that will identify you individually. If, however, you have concerns about confidentiality, please feel free to call me and we can discuss them.

I do hope that you will be willing to complete the survey. It will be a great help to me, and it will allow me to describe All Saints in the most accurate way possible. Thank you, in advance, for your consideration and assistance.

Sincerely,  
Jane F. Maynard

## Congregational Survey All Saints' Parish

I am currently studying All Saints Parish as part of my dissertation. As part of that study, I would like to have information from a variety of the church's members. Please take a few minutes to respond to these questions – in most cases, you can just check (X) the response that fits you best or fill in a brief answer. There are no “right” answers. Where you can't answer, feel free to skip to the next item. If you are uncertain, do your best to answer in a way that makes sense to you. **Note that your responses are completely anonymous.** Please return your survey to me in the enclosed, stamped self-addressed envelope by April 15. Thank you in advance for your cooperation.

### First, questions about your church and community activities:

1. How long have you been attending this parish? Mean = 12.58 years, Range= from 3 - 43 years, median = 6 years  
Are you a member? ☐ yes (20) ☐ no (0)

2. Have you ever belonged to a congregation of a different denomination? ☐ yes ☐ no  
If so, which denomination? Yes - 13, No - 6, 1 - no response, see attached sheet

3. About how often do you participate in each of the following parish activities?

	<u>Daily</u>	<u>Weekly</u>	<u>2-3 times</u>	<u>once a</u>	<u>a few times</u>	<u>never</u>
		<u>or more</u>	<u>a month</u>	<u>month</u>	<u>a year</u>	
Worship services	0	9	2	2	6	1
Education classes	0	0	3	1	3	4
Choir	0	4	0	0	0	7
Community/ social ministry	0	0	1	1	1	9
Fellowship activities	0	1	2	1	6	6
Church building upkeep	0	0	1	0	2	7
Private prayer & meditation	9	2	1	1	2	3
Diocesan ministries	1	0	0	0	3	8

4. Go back to the list above and place a check to the left of any activities in which you have leadership responsibilities (teaching, committee membership, etc.)
5. How many members of your household are regular attenders of All Saints? \_\_\_\_\_

0=8, (40%) 1=9, (45%) 2=3 (15%)

6. Think for a moment of your five closest friends. How many are members of All Saints? 0=14 (70%), 1=3, (15%) 2=2, (10%) 3=1 (5%)

7. How long does it take you to travel from home to church (one way)? Mean = 19.2 min.

8. About how much does your household contribute to the congregation each year?

[ ] less than \$100 - 2 [ ] \$100-599 - 7 [ ] \$600-1199 - 4 [ ] \$1200-1799 - 2  
[ ] \$1800-2399 - 1 [ ] \$2400 or more - 4

### Now some questions about your beliefs and values

9. Which best describes your view of the Bible?

- It is an important piece of literature, but is largely irrelevant to our lives today -- 0
- It is the record of many peoples' experience with God and is a useful guide for individual Christians in their search for basic moral and religious teachings -- 9
- It is the Word of God and its stories and teachings provide a powerful motivation as we work toward God's reign in the world -- 8
- It is the inspired, authoritative Word of God that is without error in all that it says about faith and morals -- 1
- It is the inspired Word of God, without error not only in matters of faith, but also in historical, scientific, geographic and other secular matters -- 1  
The King James is very beautiful (added by one respondent)

10. When you think about the qualities of a good Christian life, how important are each of the following to you? (Rate each one)

	<u>Essential</u>	<u>Very important</u>	<u>Somewhat important</u>	<u>Not at all important</u>
Reading & studying the Bible regularly	2	10	4	1
Spending time in prayer & meditation	14	4	0	1
Actively seeking social & economic justice	8	3	5	3
Taking care of the sick & needy	9	7	3	0
Attending church regularly	8	6	3	2
Receiving the				

sacraments	9	6	2	1
Seeking to bring others to faith in Christ	5	7	5	2
	<u>Essential</u>	<u>Very important</u>	<u>Somewhat important</u>	<u>Not at all important</u>
Seeking to bring beauty into the world	9	4	6	0
Practicing Christian values in home, work & school	11	7	0	0

11. When you imagine what God is like, which of these pictures is likely to come to mind?

	<u>Very likely</u>	<u>Somewhat likely</u>	<u>Not at all likely</u>
Father	8	4	5
Mother	6	5	6
Creator	15	2	0
Deliverer	11	5	1
Judge	8	7	3
Comforter	17	1	1
Liberator	16	2	1
Savior	15	3	1
Other = see sheet			

12. When you think about priorities for All Saints' activities in the community, how important are each of the following to you? (Rate each one)

	<u>Essential</u>	<u>Very important</u>	<u>Somewhat important</u>	<u>Not at all important</u>
Supporting social action groups in the church	2	9	5	1
Encouraging members to share their faith	3	8	5	0
Providing aid & services to people in need	6	7	4	0
An active evangelism program inviting the unchurched	2	6	8	1
Cooperation with other religious groups for community improvement	2	12	3	0

Preparing people for the

world to come where the  
cares of the world will be  
absent

0

8

4

5

Congregational participation  
in social & political issues

3

7

6

1

Essential

Very  
important

Somewhat  
important

Not at all  
important

Helping members as  
individuals to be good  
citizens

7

9

4

0

Encouraging the rector  
to speak out on

social & political issues

2

8

9

1

Fostering an appreciation of  
diversity in church & world

10

7

3

0

### Finally, some background information about yourself

13. How many years have you lived in your current community? Mean = 19.2 years

14. What is your highest level of formal education? See attached sheet

- ☐ less than high school   ☐ high school diploma   ☐ some post high school work  
☐ 4 year college degree   ☐ post college or graduate work or degree

15. What is your approximate total annual household income? See attached sheet

- ☐ under \$10,000   ☐ \$10,000-19,000   ☐ \$20,000-\$34,999  
☐ \$35,000-49,999   ☐ \$50,000-64,999   ☐ \$80,000 or more

16. Please describe the makeup of your household: See attached sheet

- ☐ live alone   ☐ live with partner and/or children   ☐ live with roommate(s)  
☐ live with spouse and/or children

17. From what part of the world do you trace your family tree? See attached sheet

- ☐ Africa   ☐ Asia   ☐ Europe   ☐ North America (i.e., Native American)  
☐ Latin America   ☐ Caribbean   ☐ Pacific Islands   ☐ Middle East   ☐ Other \_\_\_\_

17. What is your occupation (or what was it before you retired)? See attached sheet

18. How often do you attend Sunday worship at All Saints in an average month? See attached sheet

20. Do you attend the 8 a.m. (3) or 10 a.m. (13) service? Both =2, Other = 2, n/a=1

# **Collated Results of Congregational Survey** **All Saints' Parish**

## **I. Church and Community Activities**

How long have you been attending this parish? Are you a member?

3 years	yes
a few years (3)	yes
3.5 years	yes
3.5 years	yes
4 years	yes
4 years	yes
4.5 years	yes
5 or so years	yes
5+ years	yes
6 years	yes
6 years	yes
7 years	yes
12+ years	yes
13 years	yes
20 years	yes
23 years	yes
25 years	yes
26 years	yes
35 years	yes
43 years	yes

## 2. Have you ever belonged to a congregation of a different denomination?

No -- 6

Yes -- 13

No response -- 1

Baptist -- 4

Congregational -- 1

Disciples of Christ -- 1

Lutheran -- 2

Methodist -- 1

Presbyterian -- 1

Roman Catholic -- 2

Roman Catholic, Greek and Russian Orthodox -- 1

## 3. Summarized on sheet

4. Summarized on sheet

5. How many members of your household are regular attenders of All Saints?

0 -- 8

1 (Myself) -- 9

2 -- 3

6. Think for a minute of your five closest friends. How many are members of All Saints?

0 -- 14

1 -- 3

2 -- 2

3 -- 1

7. How long does it take you to travel from home to church (one way)?

10 minutes -- 6

15 minutes -- 5

20 minutes -- 4

20 minutes Sun. morn -- 1 hr. Thurs or Sat morn

25 minutes to 1 hour

30 minutes

on Sunday, 45 minutes to one hour and 15 minutes

No response -- 1

8. About how much does your household contribute to the congregation each year?

Less than \$100 -- 2

\$100 -- 599 -- 7

\$600 -- 1199 -- 4

\$1200 -- 1799 -- 2

\$1800 -- 2399 -- 1

\$2400 or more -- 4

## **II. Questions about beliefs and values**

9. See summary on sheet

10. See summary on sheet

11. Other images offered for God:

God as invisible message



Ineffable spirit – very likely  
Divine light – somewhat likely  
uncreated light; flow  
God as “everything” – very likely  
Wisdom – very likely  
Truer and truer is God within creating with truth  
Beyond conception – very likely  
Can’t be captured in a single image

12. See summary on sheet

### **III. Background information about respondents**

13. How many years have you lived in your current community?

2  
4  
8.3  
9 -- 2  
10  
13  
14  
15  
17  
19  
22 -- 2  
25  
25.5  
28  
34  
35  
54

One respondent who has households in two communities has lived in one community 28 years and in the other for four years.

14. What is your highest level of formal education?

Less than high school -- 1  
high school diploma -- 3  
some post high school work -- 4  
4 year college degree -- 3  
post college or graduate work -- 9

15. What is your approximate total annual household income?

Under \$10,000 -- 1  
 \$10,000 – 19,000 -- 5  
 \$20,000 – 34, 999 -- 2  
 \$35,000 – 49,999 -- 1  
 \$50,000 – 64,999 -- 4  
 \$80,000 or more – 7

16. Please describe the makeup of your household:

live alone -- 9  
 live with partner and/or children -- 3  
 live with roommate(s) -- 1  
 live with spouse and/or children -- 7

17. From what part of the world do you trace your family tree?

Africa -- 1  
 Asia  
 Europe – 13  
 North America  
 Latin America  
 Caribbean  
 Pacific Islands  
 Middle East  
 Other -- 1  
 Europe and N. America – 1  
 Africa and N. America – 2  
 Europe and L. America – 1  
 N. American and L. America – 1

18. What is your occupation or what was it before you retired?

Home health aide	engineering manager
mediator	sales
housekeeper	legal secretary
warehouseman	homemaker
market consultant	registered nurse
researcher/writer	student
free lance photographer, writer, maritime historian	manager
substitute teacher	accounts maintenance clerk
educator	librarian
clergy	administrative officer

19. How often do you attend Sunday worship at All Saints in an average month?

0 - 3  
less than once - 2  
1 -- 2  
2  
2-3 -- 2  
3  
3-4 - 4  
4 - 3  
4.3 - 1  
4 - 5 - 1

Two respondents are shut-ins who receive communion regularly at home.

20. Do you attend the:

8 a.m. -- 2  
10 a.m. - 11  
Both -- 2

## APPENDIX IV INDIVIDUAL INTERVIEW PROTOCOL

This appendix provides an overview of the questions that were used in interviews with parishioners to assess their bereavement resulting from AIDS. The interview began with the two open-ended questions in bold print. Following that, the interviewer assessed the parishioner's response to AIDS loss using the remainder of the questions. The protocol provided a guide for the discussion, but it was not slavishly followed. Wherever possible, the interviewer allowed the parishioner's concern to guide the flow of the interview.

### Open -Ended Questions

**Could you tell me the story of your experience with AIDS and AIDS losses? I am particularly interested in discovering how these have influenced your participation at All Saints?**

1. Describe your encounter with HIV/AIDS. When did it begin?
2. How many people have you known that have died of AIDS? How many of those have been close friends or lovers?
3. How has AIDS affected your life?
4. What meaning does AIDS have for you? Has this changed over time? If so, how? What images would you use to describe AIDS?
3. In your opinion, are the AIDS-related losses you have experienced unique or are they like other losses? If they are unique, in what ways are they unique?
4. What has it been like grieving these losses? Has the way you have grieved them changed over time? Has anything made grieving them difficult for you?
5. Besides losing loved ones, have you experienced other significant losses as a result of HIV/AIDS?
6. Have any of your losses to HIV/AIDS overshadowed the others? If so, which ones? How would you explain the special impact of this (these) loss(es)?
7. Do you know your serostatus? If so, how has this knowledge affected the way you live and the choices you make?
8. What is the greatest source of meaning in your life? Has this changed for you as a result of your encounter with HIV/AIDS? If so, how?

9. What experience or aspect of your life has most helped you to cope with HIV/AIDS?
10. What religious resources (prayer, Bible, rituals) have you drawn on in coping with AIDS losses? Have they been helpful? Have any other resources been helpful?
11. What wisdom or learning would you offer to others who have experienced AIDS losses?
12. Has your experience with HIV/AIDS affected your spiritual life in any particular ways?
13. Has your experience with HIV/AIDS affected your sexuality in any particular ways?
14. Has your experience with HIV/AIDS had any particular effect on your relationship with All Saints? With the larger church?
14. Have your AIDS losses had any impact on the important relationships in your life? On your community?
15. Has your experience with HIV/AIDS affected your view of death? Of your own death? Of the future? Did your encounter with HIV/AIDS ever lead you to consider taking your own life?
16. Did anything in you die as a result of your encounter with HIV/AIDS? If so, what? What did or will resurrection look like?
17. Have your experiences with HIV/AIDS affected your understanding of God? Your relationship with God? If so, how?
18. How do you make sense of the suffering due to HIV/AIDS? Has AIDS changed your understanding of suffering in any specific ways?
19. How do you understand the fact that you are alive whereas so many others have died from AIDS?
20. What do you think has happened to your departed loved ones? What do you think you will experience after your own death? Have your opinions on these matters changed as a result of your encounter with HIV/AIDS?
21. What do you see as the purpose of your life? Has your experience with HIV/AIDS changed your views on this subject in any way?

22. Is there anything else you think I should know about your experience with HIV and AIDS? What has it been like for you to talk about this?

## APPENDIX V

### DEMOGRAPHIC QUESTIONNAIRE

This appendix, based on a questionnaire adapted from Shrader's study of HIV-positive men, summarizes the demographic characteristics of the individual interviewees. A total of fourteen individuals were interviewed, however, I did not collect data on all questions for the three clergy interviewees. Where data are available, they are included. Two interviewees failed to return their questionnaires.

1. Age: Mean= 53.6 yrs, The age of interviewees ranged from mid 40s to late 70s.
2. Occupation: Professional/managerial = 2, education = 3, retired/disabled = 2, self employed/homemaker = 2.
3. Annual Income: One interviewee left this blank.
  - a. 0 - \$10,000 -- 0
  - b. \$10 - 30,000 -- 1
  - c. \$30 - 50,000 -- 5
  - d. \$50 - 70,000 -- 1
  - e. \$70- 100,000 -- 0
  - f. \$100,000-120,000 -- 1
  - g. \$120,000+ -- 1
4. Ethnic background (check all that apply):

Asian American -- 0	Caucasian -- 9
African American -- 1	Native American -- 0
Hispanic or Latino -- 0	Other (please specify) -- 0
5. Highest level of education completed

Grade school -- 0	4 year college degree -- 2
Junior High School -- 0	Masters degree -- 5
Some High School -- 0	Doctoral degree -- 1
High School Diploma -- 0	
Some college training -- 2	
6. Current living situation

Live alone -- 2
Live with platonic roommate -- 1
Live with spouse and/or children -- 4
Live with significant other -- 2

Live with family of origin or relative -- 0

Other -- 1

7. If you are gay or lesbian, era in which you “came out” and/or became sexually active:

- a. pre 1970 (specify when) -- 2 (late 1960s)
- b. 1970-75 -- 2
- c. 1975-80 -- 1
- d. 1980-85 -- 0
- e. 1985-90 -- 1
- f. 1990+ -- 0

8. If you are heterosexual, era in which you became sexually active:

- a. pre 1970 -- 3
- b. 1970-75 -- 1
- c. 1975-80 -- 0
- d. 1980-85 -- 0
- e. 1985-90 -- 0
- f. 1990+ -- 0

9. Date of first AIDS-related loss: Mode = 1984, Range = 1982 to 1991

10. Date of most recent AIDS-related loss: Mode = 1997, 1998 (tied), Range = 1994 to 2000

11. Number of people/acquaintances you’ve known who have died of AIDS: (please do NOT include close friends/loved ones)( If you cannot give a precise number, please estimate) : Range = 5 to more than 200 (12 responses total), Mean = 52.9

12. Number of close friends/loved ones who have died of AIDS: Mean = 9, Range = 0 to 30 (12 responses)

13. Number of people you currently know who have AIDS (please do NOT include close friends/loved ones) (If you cannot give a precise number, please estimate.): Mean = 14.09, Range = 1 to 100 (11 responses)

14. Number of close friends/loved ones who have AIDS: Mean = 1.72, Range = 1 to 15, (11 responses).

15. Number of people you currently know who are HIV positive. (If you cannot give a precise number, please estimate.): Mean = 20.36, Range = 1 -100 (11 responses)

16. Number of close friends/loved ones currently diagnosed as being HIV positive: Mean = 2.9, Range = 0 to 15 (11 responses)



17. Have you ever been diagnosed as having AIDS? Yes = 1, No = 9.
18. Have you been diagnosed as being HIV positive? Yes = 2, No = 9.
19. Have you ever sought any professional assistance specifically for coping with your losses? (i.e., counseling, support groups, psychotherapy. If so, please specify which):  
No = 6, Psychiatrist = 1, Group = 2, Counseling = 1, 12 step group = 1
20. Have you experienced the deaths of others close to you in recent years from any other causes? If so, who? No = 2, Yes = 9 (various)
21. How long have you been attending All Saints' Church? Mean = 17.6 years, Range = 4 to over 30 years.
22. Are you a member of the parish? Yes = 10
23. Do you pledge? Y= 10
24. Which statement best describes your prior religious history before attending All Saints? Please circle all that apply:
- a. cradle Episcopalian -- 1
  - b. prior Episcopalian and member of another Episcopal church -- 7
  - c. Roman Catholic -- 1
  - d. mainline Protestant (Methodist, Presbyterian, UCC) -- 3
  - e. evangelical, Baptist or free church -- 1
  - f. no prior religious affiliation -- 0
  - g. other -- 0
25. Have you participated in any other AIDS-related research? No = 7, Yes = 3
26. Are you currently a caregiver to someone living with AIDS? If so, what is your relationship to that person? (partner, friend, acquaintance) No = 7, Yes = 1, Blank = 2

## APPENDIX VI GROUP INTERVIEW PROTOCOL

This appendix contains the list of questions that guided the group interview held on 25 April 2000. Three parishioners, two gay men and one heterosexual man, participated in the interview. Each of these men had been interviewed previously in the individual interview phase. All of them had been present at All Saints during the death of the first parishioner to AIDS.

1. What would you identify as the first significant loss for AS?  
the last significant loss for AS?  
the most significant loss for AS?
2. What was AS like before, during and after the AIDS losses? How was it changed through the experience of the losses? What does the future hold and how has your history of loss affected that?
3. How did your membership at AS make a difference to you in grieving your individual losses?
4. Does it make sense to talk about communal bereavement? How did the community as a whole grieve its losses? What things helped the community as a whole to cope with them?
5. How did the parish's grieving process change over time?
6. What was lost (besides people) for All Saints?
7. What effects has the loss had on the theology of AS? the ministry of AS? the spirituality of AS?
8. What do you want the larger church to know about AS experience of loss? What wisdom would you offer to other church communities experiencing multiple AIDS loss?

## APPENDIX VII CATEGORIES EMERGING FROM FIELD NOTES

### Introduction

The purpose of this appendix is to provide the reader with an overview of the categories that emerged from the field notes. The concepts are grouped into categories in this presentation. These categories and concepts provide a summary of contents of 96 pages of field notes.

### Concepts Grouped By Category

#### Category 1: Immanence of God

Dualism (sermon theme)  
Immanence of God  
Incarnation

#### Category 2: Sacredness/Transcendence of Worship

Seasonal variations in liturgy  
Marian devotion  
Order of service  
Worship setting  
Mystery of worship  
Emotions in liturgy  
Liturgy as container  
Anglo-Catholic trappings  
Movement  
Transcendence  
Sensory stimulation  
Ritual acts  
Beauty of appointments  
Drama of liturgy  
Prayer  
Gesture of worship  
Liturgical dress  
Solemnity of liturgy  
Chanting  
Intercessions

#### Category 3: Vulnerability

Surrender  
Fear

Recovery  
Vulnerability  
Sanctity (sermon theme)  
Being led to a new land

Category 4: Worship attendance/ participation

Preparation for worship  
Lay participation in worship  
Music  
Preaching  
Mistakes in liturgy and music  
Attendance at worship  
Liturgical evaluation  
Discordance in worship  
Demographics of congregation  
Deacons  
Liturgical leadership

Category 5: Interpersonal relationships and their qualities

Sense of humor  
Parishioner relationships  
Friendship  
Warmth  
Fellowship  
Family  
History of parish  
Stewardship  
Important members  
Love  
Generosity of parish  
Grace

Category 6: Ministry

Ecclesiology  
Vocation  
Individualism  
Church  
Lay leadership/ministry  
Adult education class  
Pastoral care  
Youth ministry  
Food program

Collegiality among clergy  
Ministry partnerships  
Kenneth  
Staffing issues

#### Category 7: Inclusion

Inclusion  
Faith  
Children  
Hospitality (sermon theme)  
Sexuality  
Pets  
Urban location  
Intercessions  
Homeless people  
Inclusivity  
Unity  
Gay and lesbian issues  
Language for worship  
Eucharist

#### Category 8: Hospitality

Hospitality (practice)  
Visitors to All Saints  
Coffee hour conversation

#### Category 9: Communion of saints/remembrance

Remembrance (sermon theme)  
Communion of saints  
Memorial gifts  
Columbarium  
Types of services  
Loss of members

#### Category 10: Paschal mystery/Resurrection Life

Resurrection Life  
Laments  
Anointing  
Grief  
Social justice  
Paschal mystery

Angels  
Lazarus syndrome  
Sacrifice  
Illness  
Death

## APPENDIX VIII CATEGORIES EMERGING FROM INDIVIDUAL INTERVIEWS

### Introduction

The purpose of this appendix is to provide a summary of the individual interviews. The following list shows the major concepts that emerged, grouped by category. This list summarizes the contents of the nearly 400 pages of interview transcripts.

### Concepts Grouped by Category

#### Category 1: Early Experiences with HIV and AIDS

- First knowledge of AIDS
- Hidden early cases of AIDS
- Rapid growth in number of people presenting symptoms
- Unknown nature of disease in early days
- Lack of knowledge of HIV in early days among medical professionals
- First AS Aids Loss
- AIDS Losses at All Saints
- Communion Cup
- Rapidity of death in early days of AIDS
- Death of a close friend made the epidemic more real
- AIDS losses become personal
- First losses to AIDS
- Pastoral losses

#### Category 2: Gay Lifestyle and AIDS

- Gay lifestyle
- Castro
- Coming out
- AA meeting for people with AIDS
- Acquaintances
- Bay Area Reporter
- AIDS in Gay Friendship Circle
- Double bind of addressing AIDS as gay man

#### Category 3: AIDS – Meaning, Diagnosis, Management

- Stigma of HIV and AIDS
- Issues around testing serostatus
- Effects of knowledge of serostatus
- Disclosure of HIV status
- Life changes following diagnosis

Population affected by HIV is changing  
Importance of being open-minded about existence of AIDS  
Treatment issues  
Medical management of AIDS  
Health crises of PWAs  
Images/Meaning of AIDS  
How the meaning of AIDS has changed over time  
AIDS as a product of invincibility of the young  
AIDS affects African Americans  
Drugs and HIV

#### Category 4: AIDS Death

Increased awareness of death  
PWA plans for work replacement in event of death  
PWA anticipates death  
Threshold of death  
Events at moment of death  
Aftermath of death  
Notification of death  
Burial  
Effects on view of death  
Defining oneself in terms of death

#### Category 5: Psychological, relational effects of AIDS

Effects of AIDS  
Positive effects of AIDS  
Effects of AIDS on sexuality  
Effects of AIDS losses on relationships  
Effects of HIV and AIDS on views of future  
Blessing of same sex unions as fruit of AIDS  
Effect of PWA's death  
Loss of friends

#### Category 6: Effects of AIDS on Religious Life, Spirituality, Church and Ministry

Changed understanding of God  
Effects on relationship with God  
Effects on spiritual life  
Effect of losses on All Saints  
Effects of AIDS losses on ministry  
Effects of loss on clergy

#### Category 7: Number, nature, uniqueness of losses



Number of deaths  
Number of deaths in artistic community  
AIDS losses too numerous to name everyone who has died  
Loss of a generation  
Other losses associated with AIDS  
Loss of potential  
Types of loss at All Saints  
Uniqueness of AIDS losses

#### Category 8: Overshadowing Losses

Overshadowing AIDS Losses  
First AIDS Loss at All Saints  
Stephen Wilson  
Neil Little  
Reason certain losses were overshadowing  
Notoriety of a PWA  
Qualities of deceased  
"Sad" situation  
Artistic talents of PWA

#### Category 9: Grieving AIDS Losses

Nature of grieving process  
Difficulties in grieving  
Acquaintance loss  
Saying goodbye  
Unfinished business  
Closure  
Letting go  
Multiple loss  
Anticipatory grief  
Changes in grief over time  
Suicidal thoughts  
Relationship between church and grieving process  
Surrogacy  
Family support for caretakers  
Memories  
Thoughts about the dead  
Finding emotional support for caregivers

#### Category 10: Coping -- Strategies and Resources

Resources for coping

Religious resources useful in coping  
Intercessory prayer  
Memorial gifts  
Importance of memorials  
Columbarium  
Importance of reading names  
Activism  
Volunteer work  
Suicide attempts  
Fighting HIV  
AIDS Quilt  
Talking about losses  
Adopting new coping strategies  
Alcohol use  
Funerals

#### Category 11: Feeling associated with AIDS and AIDS Losses

Fear of AIDS  
Fear of forgetting loved one  
Transmission of HIV  
Fear of becoming infected  
Fear of contagion  
Being worried well  
Ambivalence about interacting with sick and the dead  
Helplessness  
Vulnerability  
Denial  
Guilt  
Alienation from family  
Stress of many losses  
Relief  
Anger  
Hypocrisy  
Being alone  
Self-acceptance  
Acceptance  
Surprised by extent of emotion  
Isolation of PWA

#### Category 12: Relations with PWAs and their kin

Tenuousness of relationship with PWA  
Work partnership with PWA

Nature of relationship with PWA  
Close friend with AIDS  
Conflict/stresses in relationship with PWA  
Fragile state of relationship with PWA  
Notification of kin  
Relationship with kin  
Reconciliation  
Relations to deceased  
Setting boundaries with PWA  
Family of PWA

#### Category 13: Theological Reflection

Afterlife  
Resurrection  
Changed views of suffering  
What you expect after your own death  
AIDS as judgment  
What church can do about AIDS  
Justice  
Redemption  
Central theological issues

#### Category 14: Spirituality and AIDS Loss

Why you alive whereas others died  
Effects of AIDS on spirituality/faith  
Effects on views regarding church  
Purpose of life  
Survivor wisdom  
Source of meaning in life  
Spiritual care of the dying  
Dreams of PWA  
Worries about the spiritual state of PWA  
My life has got to count

#### Category 15: All Saints History

What drew S to AS  
Membership losses at AS  
Demographics  
Strengths of AS as parish  
AS as family  
Neighborhood  
Changes in neighborhood in the 60s

Pastoral leadership  
History of AS  
African American members  
Explosion of women members after 1990  
Expectations for AS future  
Fellowship  
Gay priests  
Communal bereavement at AS  
Religious history

Category 16: All Saints' AIDS Ministries

Support group for HIV-positive people  
Support from parish  
Quality of care  
Touching  
Keeping vigil  
Need to be supportive to families of PWAs  
Protective measures  
Hospital/hospice visits  
Making ethical decisions  
Discontinuing heroic care  
Caring for the sick  
Gifts for ministry at AS  
Providing practical help to PWAs  
Visitors to AS with AIDS  
Legal issues  
Crisis ministry  
Central pastoral issues at AS  
Gifts for PWAs

## APPENDIX IX CATEGORIES EMERGING FROM THE GROUP INTERVIEW

### Introduction

The purpose of this appendix is to provide a summary of the categories emerging from the group interview. Once again, this table shows how the concepts were grouped into categories. This list summarizes the twenty five page interview transcript.

### Concepts Grouped by Category

#### Category 1: Grief Process

Changes in parish's grieving process over time  
Crying  
Effect of parish membership on individual grief  
Communal bereavement  
Differences in grieving  
Intensity of emotion  
Fear of AIDS  
Styles of coping with loss

#### Category 2: Effects of AIDS Losses

Effects on ministry  
Effects of loss on parish theology  
Other AIDS losses in parish  
Changes in AS associated with AIDS  
Wisdom to share

#### Category 3: Future of All Saints

Demographic changes in the parish  
Gay partnerships  
Future of All Saints  
Non gays feel welcome at AS  
Gay men

#### Category 4: Ritual/liturgy

Funerals  
Liturgy

#### Category 5: AIDS Deaths at All Saints

AIDS as known cause of death  
AIDS deaths of non-parishioners  
Deaths at All Saints  
Number of losses

Category 6: Overshadowing losses

First significant loss at AS  
Overshadowing deaths  
Neil Little  
Stephen Wilson

Category 7: Pastoral leadership

Kenneth Schmidt  
Lloyd Prator  
Lay leadership  
Hospital visiting

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